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PUBLIC HEARING
by
Joint Legislative Committee on Aging
October 2, 1985, Columbia, SC

PUBLIC HEARING

BY

JOINT LEGISLATIVE STUDY COMMITTEE ON AGING

Columbia, October 2, 1985

Representative Patrick B. Harris, Chairman

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STATE DOCUMENTS

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The Annual Public Hearing of the Joint Legislative Study Committee on Aging was held in the Blatt House Office Building, Room 101, in Columbia, South Carolina, on Wednesday, October 2, 1985. The Hearing convened at 10:30 am.

Representative Patrick B. Harris, Chairman of the Committee, called the hearing to order. At this time he asked Dr. Julian Parrish if he would open the meeting with prayer.

In his opening remarks, Rep. Pat Harris stressed the fact that this was the peoples' meeting and the Committee was here to listen and take information in hopes that they could legislatively do a better job for the aging population.

Following this statement the members of the Committee and staff were introduced: Representative Dave Waldrop, Vice-Chairman of the Committee; Representative Dill Blackwell; Dr. Carlisle Holler, Gubernatorial Appointee; sitting in for Senator Bill Doar, Mr. Gary Spires; sitting in for Senator Isadore Lourie, Ms. Shelli Charles; and Dr. Julian Parrish, Secretary for the Committee. Also in attendance but joining at a later time was Senator Peden McLeod. Mrs. Gloria Sholin, Gubernatorial Appointee, had an unavoidable conflict and could not attend. Rep. Harris commended the Committee on their loyalty in attendance.

He also introduced the Committee staff members: Ms. Keller Barron, Director of Research and a new addition to the staff, Miss Sherri Craft, Administrative Assistant.

At this time Rep. Harris requested that Dr. Julian Parrish read a resolution for the Committee to be incorporated in the records. (Appendix A)

Representative Harris recognized Professor Alice Moore and Allen University students taking courses in gerontology.

He also welcomed members of the media. And a special thanks was extended to Mr. and Mrs. Homer Schmitt and Mrs. Anna Harris for keeping the attendance roster.

With these preliminary remarks, Rep. Harris called the first speaker.

William K. James
SC Commission on Aging
1430 Confederate Ave.
Columbia, SC 29201

Statement for Public Hearing, Wednesday, October 2, 1985

Joint Legislative Study Committee on Aging

Chairman Harris and members of the Committee, I would like to thank you for this opportunity to make this presentation on behalf of the elderly blind of South Carolina.

Last year at this time, there was no Independent Living for the Elderly Blind in our state. If you were over 65 years of age and were blind or seriously visually impaired and could not function independently, there was no hope for you unless you were one of the very few that was eligible for Vocational Rehabilitation Services. You could not expect to continue to live in your own home. Your only alternative would be to move in with a family member or be relegated to a nursing home or other institution.

On July 1 of this year, things began to change, thanks to you and other concerned legislators. The S. C. Commission for the Blind received an appropriation of \$75,000 to start an outreach program for the elderly blind. The purpose of this program is to teach basic survival skills to enable the elderly blind person to live independently in their own home, thus avoiding the need to move in with other family members or to be institutionalized. These skills are taken for granted by sighted persons. They would include such things as travel, how could you get about your own home if you weren't able to see, or even just walk down to the mailbox to see if you had any mail; activities of daily living, things such as personal care, grooming, how would you shave, for example, if you couldn't see; basic homemaking skills--how would you be able to keep your house clean if you couldn't see; or how could you prepare even simple meals; how could you even pour yourself a cup of hot coffee without burning yourself; basic communication skills--how would you write down a phone number that you needed; or how could you read a recipe that you needed; or even how could you dial a telephone to call for help if you got into trouble. In addition to providing these direct client services, it would also enable the Commission staff to work with the Commission on Aging, and personnel in nursing homes and institutions who come in contact with older persons that are blind to enable them to better meet the needs of their clients.

In order to address the needs of these clients, the Commission for the Blind received funding to hire two instructors--one Orientation and Mobility Instructor and a Rehabilitation Teacher, as well as a part-time Secretary. A van would be purchased to be equipped with aids such as braille devices and white canes to meet the specialized needs of the elderly blind. As you are aware, however, no new positions can be created until the first of the year.

Nevertheless, we have developed the regulations and have started to implement this program. We have two teams (a Rehabilitation Teacher and an Orientation and Mobility Instructor) working out of the Columbia and Greenville offices serving the vocational rehabilitation clients. As the needs of the elderly

Statement for Public Hearing, Wednesday, October 2, 1985—contd.

blind are somewhat similar, we are using these teachers to provide instruction for the elderly blind. We have begun recruiting and plan to have a Mobility Instructor and a Rehabilitation Counselor who will work out of the Charleston area by the first of the year. Whenever possible, we try to work with clients in groups of 8 to 10 in order to conserve funds, and we have also found that there is a great deal to be gained by the interaction in these small groups.

Although the program is very new, the staff and clients are very excited about it. We are now starting to meet the needs of these deserving people.

Why do we need this additional \$50,000? As I have indicated, we have just started to meet the needs of these people, while most other states have been doing this for years. There are between eight and ten thousand blind persons in South Carolina and approximately half of these people are 65 years of age or older, so with the limited resources that we have, we can only meet the most glaring needs.

We plan to contract with aids to enable us to work with larger groups. We also plan to contract with trained orientation and mobility instructors as well as teachers who have the necessary homemaking skills to work with our clients. We also ^{hope} to utilize the services of other blind persons to teach these skills whenever possible. This will enable us to establish more programs and reach more blind persons, especially in the small towns. This money would also be used to purchase low vision aids, white canes, braille devices such as watches or clocks, and other aids and appliances that enable people to function without sight.

We believe that this would enable us to double the capacity to make these services available to the elderly blind. I do not need to point out the savings which could be realized if we are able to prevent the need for institutionalization of these deserving people. There is no way to put a price tag on human dignity or the satisfaction of being able to live independently in your own home.

That's why we are requesting \$50,000. We know the need is there and we are concerned about meeting that need. You have demonstrated your concern last year in helping us start this program; therefore, I am respectfully requesting that you continue to support this very worthwhile program.

Representative Harris recognized at this time Senator Peden McLeod as being in attendance. He then called the next speaker.

Testimony by Paul B. Fowler, Ph.D.
Public Hearing of Joint Legislative Committee on Aging

Thank you for this opportunity to testify before this committee. My concern today is not to address the needs of any particular program, but rather the principles underlying such programs; and I do so in very general terms.

Several items have caught my attention in recent months. First, the percentage of elderly persons in proportion to those working is rising significantly. By 2030, the ratio is projected to be 2:1, working or retired. The economic and social problems this projection suggests would be staggering. It points out all the more the importance of this committee and the policies which we determine for the future.

The reaction of society is slowly forming. Many fine groups and churches are responding in creative and compassionate ways. They should be encouraged.

Other forces are at work, however, which run counter to these acts of compassion. I am referring, of course, to the efforts of euthanasia advocates, especially the Society For the Right to Die. Unwittingly, I think, society is presently following their lead toward promoting passive and active euthanasia.

Living Wills have already been passed in 35 states, and will probably be passed in the remaining 15 states within the next two years. Quite often the wording of these bills is done cautiously, so as not to allow abuse. But several points may be made against their enactment in general:

1. They are heralded as though they bestow the 'right' to refuse medical treatment; whereas all patients under common law already have this right.
2. They originated from and are supported by The Euthanasia Society of America, which in 1975 changed its name for euphemistic reasons to the Society for the Right to Die. Living Wills are a very important step in that society's ultimate goal of "lawful termination of human life by painless means for the purpose of avoiding unnecessary suffering."
3. The substance of Living Wills is of secondary importance to euthanasia groups (it can be very cautiously worded). The implicit acknowledgement of the "right to die" IN A LAW is the victory; a 'presumption' upon which they can build.
4. Cautious Living Will bills will later be changed to more open laws advocating the right to die in broader circumstances.

This last point has already been dramatically demonstrated by the adoption of the "Rights of the Terminally Ill Act" by the National Conference of Commissioners on Uniform State Laws on August 2-9, 1985. This Act is a model statute with the dual purpose of 'simplifying' existing living will legislation, and 'unifying' them across the

states. This Act:

- 1) views food and water as 'medical treatment' rather than basic nourishment, and establishes a climate which encourages the withholding of these in cases where life-supporting measures have been withdrawn;
- 2) fosters a view that life for the elderly and terminally ill is of no value, and death is to be desired; in doing this it also serves to encourage a lack of treatment for terminally ill patients;
- 3) broadens the discretionary powers of a physician at a point in a person's life when he/she is most vulnerable; and in its general and simplifying language it has the effect of taking away protection from the disabled and elderly; this in turn will encourage health care abuse;
- 4) appears legally to open the door to suicide, assisted suicide, non-voluntary mercy killing, etc.

Abuse under such statutes is already taking place. The Washington Post notes that physicians in a shock/trauma unit in Maryland put severely injured accident victims to death (without their knowledge or consent) by lethal injection. It is reported that doctors in Seattle 'allow' the elderly in nursing homes to die from fever, influenza, or pneumonia. The living will bill has caught the attention of cost-control officials as a means of cutting Medicaid costs. Passing this act will simply serve to make such abuses acceptable under the cloak of law.

Those who stand in greatest jeopardy from this kind of legislation are the elderly, the handicapped, and other 'disvalued' patients. Since being 'allowed' to die from starvation or dehydration is far from pleasant, it is already being suggested in medical literature that giving someone a lethal injection would be far more merciful.

Those behind this movement for the 'option of death' play on the fear of dying, the cost of care, the lack of alternatives. Their platform is 'quality of life.' Why this fixation on the subtle joys of the 'right to die' on demand? Why not advocate instead something else of genuine benefit to patients such as 'merciful care' options?

What then can government do? Government is not the 'sole' answer; but it is a very important 'part' of the answer. Legislators can perform a two-fold role:

1. LAW. Possibly the most important moral function of government is to protect the weak from the strong. The underlying principles "Thou shalt not kill," and "Thou shalt not steal," are essential in a just and compassionate society. We must make sure that laws

protecting the weak (in this case, the elderly) from the strong are kept in force; and laws which have the effect of taking away that protection are not enacted.

2. MORAL LEADERSHIP. You, as our elected legislators, can provide good moral leadership. You must pave the way not for simplistic solutions -- e.g., get rid of people-problems by getting rid of people; but for compassionate solutions -- caring, suffering with, upholding people with problems.

We may be facing an uphill battle in this regard, due to the breakdown of the American family; hence less people to care for the elderly; also more elderly living alone, without a spouse or other family member; and the general lack of a sense of obligation by the children of the elderly.

It would be wonderful if there were no weak or unwanted people among us. But the measure of our Christianity - indeed, of our humanity - is not that there are no 'unwanted' ones, but what we do with those who are unwanted. Will we eliminate them through passive or active euthanasia, or will we love, care for, and provide for their needs?

Thank you.

Paul B. Fowler

Mr. Chairman, and members of the Joint Legislative Committee to Conduct Continuing Studies of Public and Private Services, Programs and Facilities for the Aging:

My name is Alfred Rawlinson and I have been entrusted by the Legislative Forum of the South Carolina Federation of Older Americans to present to you three of their concerns with hopes we will solicit your interest and support.

The first: is the so-called "Death with Dignity, or Living Will", House Bill #2041. This legislation would allow an adult to make a written declaration instructing his or her physician to withhold or withdraw life-sustaining procedures in the event his or her condition is terminal and there is no hope of recovery. The bill states that it does not authorize or approve of mercy killing, deliberate omissions of acts that will end life, other than to permit the natural process of dying. This bill passed the House, and is now on third reading, with amendments, in the Senate. 35 states have similar legislation. Let us take this opportunity and reverse what happens too frequently - we are the low man on the totem pole!

The Second: is the bill revising the Probate Code. This 500 page bill - with many commentaries - has passed the House #2792 and Senate #481 was referred to a ~~subcommittee~~ committee on April 16, 1985. A hearing will be held on it on October 9th, at 2 P.M. in Suite 105, Gressette Building. These would collect, consolidate and revise aspects of the law relating to general probate. The matter has been exhaustively studied by various groups for twenty years. The Forum feels that the simplification it provides would benefit the elderly.

Third, and finally, and of the utmost importance are present considerations being given to redefining the units below the state level to be used in distribution of federal and state funds and for administrative and service programs. At present the state has 9 groups of counties and 6 individual counties for these functions. The attempt to equate groups of counties and single counties in

equitable programs presents many complications because of the mixture of various units of different structures.

Planning and service areas of various sizes have been proposed:

- (1) Four multiple county ~~units~~ areas;
- (2) Five multi-county areas;
- (3) Six multi-county areas;
- (4) Ten multi-county areas;
- (5) Nine multi-county ~~units~~ ^{units} and six single county planning and service areas - a total of 15, which is the current situation; and
- (6) 46 single county units or service areas.

Those receiving most study include:

- (1) Four multi-county units;
- (2) Maintaining the current status quo - nine multi-county units and six single county planning and service areas;
- (3) Ten multi-county areas; and
- (4) Forty-six single county areas.

The Forum strongly recommends a return to the use of ten multi-county planning and service areas, which has been the main basis since 1973. Areas which are too large - such as four multi-county areas - separate those who do the planning at too great a distance from those they serve. Also, such areas might make the obtaining of local contributions and support more difficult. At the other extreme, 46 units would place undue burden on the central state administrative body. Any radical change from the status quo would be adopting an unproven system which might weaken the aging delivery system in the drastic change over. The ten multi-county areas follows the planning districts established by Executive Order of Governor McNair and are based on economic factors. This was the pattern followed for some years and the Forum feels it should be returned to. We feel it would take a minimum of readjustment and would give assurance of highest quality service programs through adequate monitoring, evaluation, and

technical assistance by area staffs. Also, it would prove closer to both clients and local governments. Altho the comparison is not complete there is enough similarity to make my point. The reduction of counties in South Carolina from 46 to say 13 would be a cause of consternation and confusion resulting in weakened services to localities during a long readjustment period.

Georgia has 18 service areas; Florida has 11; North Carolina has 18; Mississippi has 10; Tennessee has 9; Kentucky has 15; and Alabama has 12. None of these areas ^{are} ~~is~~ the multi-county and single county service areas.

We feel that 10 service areas for South Carolina is the most efficient and tried set-up.

In summary, the Legislative Forum asks your interest and support for:

- (1) House Bill #2041 - "Death with Dignity";
- (2) Senate Bill #481 - Probate Code Revision and consolidation; and
- (3) A return to the ten-multi-county planning and service areas in the distribution of federal and state funds and service planning and delivery ~~xxxx~~ for and with the the aging in South Carolina, in lieu of any drastic revision.

These are/but some of the problems and opportunities in the field of aging in South Carolina with which your Committee has had a distinguished record of achievement in past years, This we appreciate and look forward with confidence to your continuing work.

Representative Harris stated that the concern is not how but what is best to get these services out. A compilation of Mr. Bryan's study and the study the Committee has authorized will enable the Committee to talk knowledgeably. Representative Harris said he would see to it that the SC Federation of Older Americans would be furnished with a copy of the study.

**STATEMENT FOR SOUTH CAROLINA STATE LEGISLATIVE COMMITTEE
AMERICAN ASSOCIATION OF RETIRED PERSONS**

**BEFORE THE
JOINT LEGISLATIVE STUDY COMMITTEE ON AGING
COLUMBIA, SOUTH CAROLINA
OCTOBER 2, 1985**

**PRESENTED BY
EVERETTE M. DEAN
CHAIRMAN, SOUTH CAROLINA STATE
LEGISLATIVE COMMITTEE, AARP**

It is an honor and a privilege to present to the Joint Legislative Committee on Aging some of the concerns of members of the South Carolina chapters and units of the American Association of Retired Persons.

In April, May, and June of this year, the American Association of Retired Persons' membership in South Carolina was surveyed by the State Legislative Committee to help determine the most important legislative concerns of the chapters and units. After reviewing all of the responses submitted by 16 AARP chapters and 22 SCREA (South Carolina Retired Educators Association) units, our State Legislative Committee identified the following 1986 legislative objectives for which we are seeking your support:

Legislative Priorities for 1986

1. Enact a revised South Carolina Probate Code, establishing a process for probating estates with savings of time and costs.
2. Restrain the rise in health care costs in South Carolina through appropriate means including hospital budget review and rate-setting if necessary.
3. Continue the cost-of-living increase for retired state employees and retired teachers.
4. Delay institutionalization of frail elderly by establishing a statewide community services program including home health care, transportation, and homemaker/chore services, and by providing financial incentives for families to care for their older relatives at home.
5. Maintain an adequate homestead exemption program for elderly homeowners.
6. Assure medicare and medicaid recipients access to health care services and facilities without discrimination.

1. The first legislative priority is to enact a revised South Carolina Probate Code. For several years, AARP chapters and SCREA units have advocated the enactment of legislation designed to improve the South Carolina Probate Code. There is an almost unanimous opinion by the membership that the Probate Code

should be revised to establish a process for probating estates with a savings of time and costs. An incalculable number of words have been written and spoken on this subject. Although progress has been made toward enactment of an appropriate bill, the goal has not yet been reached. We sincerely hope that 1986 will be the year in which it will be attained.

2. The second legislative priority (restraining the rise in health care cost in South Carolina) is of utmost importance to every South Carolinian and especially to the elderly of the state. This priority is also receiving primary attention by the National Legislative Council and the Board of Directors of AARP which represents 19 million members of the organization across the nation. This priority refers to the critical need to restrain the extraordinary rate of increase in health care costs in general and hospital costs in particular. Health care spending rose 9.1% in 1984. This is more than double the rise in the Consumer Price Index for the same year. In this regard, the AARP has launched a nationwide health care campaign. We, the members of AARP in South Carolina, as well as our counterparts throughout the country, see cost containment as the single most important factor determining the quality of our health care.

Over one billion dollars a day is being spent in the United States on health care. Expenditures in this area have been sky-rocketing at more than double the general inflation rate. At stake in this cost crisis is not only affordable health care for older Americans but also for all Americans. Hospital costs, in particular, have soared. According to the Bureau of Labor statistics, the increases in hospital room rates have been two and one-half times greater than the increases in general price levels. Not only has Medicare been threatened by the health cost crisis, but private insurance plans have been also jeopardized.

We are seeking your support in bringing South Carolina to a position of leadership by enacting legislation to restrain the rise in health care costs: This

crisis is a threat not only to the elderly, but to every South Carolinian.

3. In priority three, we are requesting that you continue a Cost-Of-Living increase for retired state employees and retired teachers. We believe that this request is justified in view of the current rate of general inflation, the fact that an increase in retirement benefits for retired state employees and retired teachers was eliminated from the budget year before last, and when received recently the bonus has been for 1%. The need is obvious; therefore, I shall not belabor that point. In order to help retired persons cope with inflation losses in recent years, we maintain that a cost-of-living increase in retirement benefits is imperative and fair.

4. The fourth priority is to delay institutionalization of frail elderly by establishing a statewide community services program including home health care, transportation, and homemaker/chore services, and by providing financial incentives for families to care for their older relatives at home.

We feel that the frail elderly are much happier if they can remain at home or with relatives in an environment with which they are familiar. Providing these services and incentives for families to care for older relatives we believe will also result in a much lower cost to the state than placing these persons in nursing homes.

5. Priority five is to maintain an adequate homestead exemption. The reassessment of property and the levying of higher and higher property taxes have made the present homestead exemption most inadequate for elderly people. The AARP maintains that increasing the homestead exemption is the best means for delivering property tax relief to older citizens since the overwhelming majority of the elderly are on a fixed income. This is a very strong legislative priority of our constituents. We urge immediate passage of an appropriate bill.

6. The sixth priority is to assure Medicare and Medicaid recipients access to health care services and facilities without discrimination.

We believe that all South Carolina Medicare and Medicaid recipients should have access to health care services and facilities without regard to prestige, standing in the community, race, or any other method of showing favoritism.

We appreciate very much the attention that the State Legislature has given to the needs of older citizens in the past, and we solicit your continued support of this ever-growing segment of the population of South Carolina.

Jim Hollingsworth
512 Carpenter Rd.
Charleston, SC 29412

Mr. Hollingsworth's written remarks were requested but not submitted. He presented testimony entitled "Slippery Slope" which centered around the 1)unborn dead 2)newborn dead and 3)long-born dead.

Representative Blackwell interrupted the presentation and asked how this topic was related to the Committee on Aging.

Mr. Hollingsworth replied that we need a reverence for life. We are headed toward eliminating people based on utility.

Representative Harris called for the next speaker.

Marie Annette M. McKinney
104 Elm Circle
Summerville, SC 29483

Ms. McKinney's written remarks were requested but were not submitted. She presented testimony in opposition of the Living Will legislation. Ms. McKinney represented the SC Citizens for Life and stressed these points:

- not surrendering to the elements
- developing a healthy system which possesses a reverence for the elderly and gives them a reason to live.
- the Living Will bill provides legal protection for doctors and not the patient.

Representative Waldrop asked how Ms. McKinney qualified not having the bill.

Ms. McKinney replied that it is not needed. They already have the right to refuse treatment.

Oct.2, 1985

-17-

Lorraine Bate Orr
139½ Broad St.
Charleston, SC 92401

To The Joint Legislative Study Committee on the Aging of S.C.
from Lorraine Bate Orr, Chair, S.C. Society for the Right to Die

When my husband, John, died officially in 1983, he had died ⁱⁿ ~~spiritually~~ long before, his brain dulled by pain or morphine, his joy in life so long gone it could hardly be recalled. He wanted to accept the kindly decree of death but his doctors did not. They kept him alive by artificial means, in spite of his wishes and his signature on the Living Will. In June of 1981, John complained to the doctor of a sore throat, (he'd smoked a pack and a half of cigarettes since his teens). He was given two rounds of antibiotics. In August, a biopsy showed cancer of the left tonsil. In September he was operated on and the cancer had metastasized. I think his life might have been saved but it wasn't. And when he should have been allowed to die, they wouldn't let him. A lawyer offered to bring suit against the doctors involved, on a contingency basis, but John was a peace-loving man and I knew he'd prefer me to work through my pain and anger in a more constructive way. So I took the chair of the S.C. Society for the Right to Die, supporting the passage of the Death with Dignity Bill. This law incorporates some of the best features of similar laws passed by thirty-five states and the District of Columbia. Here are its main points: An adult can give written instructions in advance to his physician to withhold or withdraw life-sustaining procedures in the event of a terminal condition. This can be done at any time. It does not constitute suicide, nor does it permit mercy killing. The person must be declared terminal by another physician in addition to the attending physician. The statement must be witnessed by three people who have nothing to gain by the patient's death. This statement can be revoked at any time without regard to physical or mental condition. It is entirely voluntary. If you

don't want to sign it, you don't have to. While it protects the individual from being kept alive by artificial means, it also protects the physician from civil and criminal liability when carrying out the patient's wishes. Of course comfort care must be continued throughout the dying process. The history of this law in this state is pretty depressing: Four times it has failed to pass, in 1977, 1979, 1980 and 1985. I know from talks with practically every legislator in the House and the Senate that the majority favors this bill, but it gets killed every time by a determined few. Last May on the last day of the session, moves to adjourn prevented it from coming to a vote. Why do these people fear this compassionate law? A couple of them said that the law was unnecessary because the patient already has the right to refuse treatment. This is simply not so. My husband's case is the best example I can give. And probably everybody in this room can tell a horror story about someone kept alive by artificial means when the time for natural death had long since passed. Another wondered how a dying patient would be treated if he were in a coma? Well, how can his wishes be known, unless he has signed a Living Will? And remember, two physicians must concur that death is imminent. And there are those who say this bill would lead to euthanasia and they point out that the Society for the Right to Die began as the Euthanasia Society. Indeed that is so. In fact, when I was a broadcaster, I interviewed Elizabeth Halsey, the executive director of the Euthanasia Society on my program, "Good Living" over 20 years ago and when I asked her the aims of the Society her answer was the same then as mine is today: To give everyone who wants it the right to die a natural death without the intervention of extraordinary methods. "Euthanasia". It's a word that can be and is given different interpretations. When Pope John Paul II issued his Declaration on Euthanasia in 1980, he said, "In ancient times, euthanasia meant an easy death without severe suffering. In this document, euthanasia is an action or an omission which causes death in order that suffering may be eliminated." He goes on to say, in

effect, "When death is inevitable, one may refuse forms of treatment that would only secure a precarious and burdensome prolongation of life." Doesn't this describe the proposed Death with Dignity Act? But strangely, the Roman Catholic Church in South Carolina is fighting it all the way. This puzzles me. If the Church is against human interference when God decrees life begins, why then are they against His decree when life ends?

There are one or two who point to Hitler in Nazi Germany and suggest that convenience killings could become permissible through this law. Oh come on! Hitler was a dictator who observed no law...and this is America. Let's agree though that no law was ever written that couldn't be abused, except that in the case of the Living Will law there has not been one instance of abuse in any of the 35 states or the District of Columbia. Not one.

A recent Gallup poll revealed that 81% of the population would support Living Will legislation. We can assume that many of them belonged to such organizations as those which support the bill in this state: The Baptist Convention, the Lutheran Church, United Methodist Church, Christian Action Council, SC Medical and Nurses' Ass'n, the Presbyterian Church among many many others, a lot of them represented in this room today.

Part of the reason for this support must be because of the wildly unrealistic economics of this whole thing. Medicare is cut back to the degree that many who want to live and could live, can't, while the same Medicare funds they are denied go to maintaining artificial life in a person who wants to be released.

James A. Rogers
1313 Wisteria Drive
Florence, SC 29501

Thank you, Mr. Chairman, Members of the Legislative Study Committee, Ladies and Gentlemen:

It's a pleasure to be here, and a distinction to have been asked to make some remarks. I am aware of the time impose and will try to stay within the minutes allotted.

I find myself so soon, it seems, an older South Carolinian. I guess the feeling is not unusual when I wonder what has happened to the years to cause them to move on so swiftly. The other day when I reached the age of eighty, and my family thought it time to celebrate, which they did, it seemed just yesterday, or at most a few years back, when college years were just behind and entrance upon a professional career was at the threshold.

Even ten years since retirement have not slowed the pace of passing time, but they have given me some time to think about the place of older citizens in American life, and to shape a sort of philosophy for aging years, both for the person aging and for the society to which he or she belongs.

Let me begin by telling you what you no doubt already know about the ever-increasing number of us whom some like to call senior citizens. As medical science and health care practices continue to perfect ways for extending life expectancy, we are becoming an increasingly significant population factor in American society.

Consider some statistics illustrating the demographic revolution that is taking place in the United States.

In 1900 there were three million Americans over age 65, or four percent of the population.

In 1970 there were twenty million over 65, which was 10 per cent of the population.

In 1980 there were twenty-five and one-half million - eleven per cent of the population.

Some estimate that by 1990, there will be thirty-five million - 13 per cent of the population.

The U.S. Bureau of Statistics suggests that by 2030, probably 16.6 per cent of the nation's population will be over 65.

And there's yet another dimension to the story. Once they reach the age of 65, they live live longer.

In 1900 there were one million people 75 and over. 100,000 were 85 and older.

But in 1980, there were 9.5 million people 75 and older, and 2.3 million were 85 and older.

In view of these startling statistics many conclusions can be drawn, only two of which I wish to emphasize. One concerns preparation for retirement; another, utilization of retired people.

I am aware of South Carolina's concern for its aging population, as evidenced by the existence of this Legislative Study Committee, and by both private and public agencies and institutions committed to care for the aging. Such sensitivity does credit to our social awareness and is a tribute to state private and public leadership. But let me as an older citizen speak from the vantage ground of one of us and say something which I believe speaks to the best interest of both the retiree and the state.

The retired citizens of South Carolina - at least those retiring each year - have spent a lifetime of work with full commitment to their jobs. The work ethic is therefore deeply embedded in their psyche. Transition from a life of activity to one of inactivity can be and often is devastating. While some have developed a clear plan for retirement years, still others hold only vague expectations of "doing something," with no clear idea of what that "something" is to be. Failing to find a satisfying something, they are faced with a loss of identity, and for a person who has been actively conscious of his personhood in his job and in his community to become suddenly a non-person with no identity except as one who had reached retirement years with no defined plans for the future - that can be ruinous for what should be the happiest and most relaxing years of one's life. Some may prefer this loss of identity and new anonymity; but many more will feel wasted and useless. Whatever their feelings, society loses immeasurably if and when so many of its people, so deeply embedded with the work ethic, are suddenly made aware of their non-personhood.

I am therefore suggesting that society - both in its public and its private dimensions - should give thought to means by which a person can move in orderly fashion from one stage of life to another. In the United States massive resources are directed to preparing young people for adult roles, but relatively little attention is given to preparing middle-age persons for older

age roles. Therefore, the transition from middle to older age involves giving up the satisfying and often prestigious roles of adulthood and accepting those of retirement age. and frequently with little to no preparation for the change.

Sociologists speak of anticipatory socialization. By that they mean making advance preparation for retirement. It's a term applicable to both the individual person as he approaches retirement and to the state as it confronts the increasingly large percentage of the people who are moving into retirement status. Perhaps some of the best and most farsight money South Carolina could spend would be an investment in helping middle-age persons prepare for meaningful and productive retirement.

There is yet another dimension to be considered. It concerns making use of the talents and experience of retired people. Though loaded with experience, and often with wisdom and expertise, unless they have retained an important place in business and work, or identification such as chairman of the board, or in a professional role as writer, philosopher, or consultant, as examples, society loses some of its most valuable resources through benign neglect and disregard of what many of its older citizens have to offer.

The record of legislative and state agencies in reference to the use of retired talent and experience appears little better than that in the business-industrial world. The appointment of citizens to state agencies, boards, committees, etc., is usually made on

political or other pragmatic grounds. The rule seems to be to involve this person because he represents an important industry, another because he represents a certain political view, or another because of some relation to a professional group or groups. It may well be in the state's ~~best~~ *concern* ~~interest~~ for affirmative action be broadened to include programs on behalf (1) of preparing middle-age South Carolinians for retirement, and (2) making a broader and more effective utilization of the wisdom, talents, and expertise of older citizens. More often than not, they are people who are not looking for self-advancement, who are ripe in the wisdom of years, and, as a group, are concerned for programs and causes that benefit society for their own times and for future generations.

Sociologist Caroline Bird distinguishes between the old and the ageless. The old, she says, are withered, unhappy, and rigid. In contrast, the ageless are happy, imaginative, fruitful people who have maintained a capacity for growth. We have many old people in South Carolina. We also have many ageless. To make adequate provisions for the old is a social and moral imperative. To stimulate, to utilize, promote appreciation for what the ageless have to offer is both visionary and imaginative use of an extremely valuable resource.

Representative Harris thanked Mr. Rogers and asked if the Committee could get a copy of his remarks. "I would like to use them as a matter of plagiarism in the future for some talks that I might have to make." He also commended Mr. Rogers on receiving this honor and stated that the Committee has agreed to prefile a resolution recognizing his achievement.



SOUTH CAROLINA COMMISSION ON AGING

Presentation to General Assembly's Study Committee on Aging
Reverend M.L. Meadors, Chairman
10/2/85

Representative Harris, distinguished members of the General Assembly's Study Committee on Aging: I am Jack Meadors, Chairman of the South Carolina Commission on Aging.

Thank you for the opportunity to appear before you. I commend legislative progress for older South Carolinians, that is made possible by your leadership and support.

The passage of the Bill of Rights for Residents of Long-Term Care Facilities is a significant step toward our goal of assuring all older South Carolinians of respect and fair treatment, regardless of their physical and financial conditions, a goal that we know this committee shares with the Commission on Aging.

Other accomplishments that will mean a great deal to many older South Carolinians are the exemption of hearing aids from sales tax, the exemption of those 65 and older from the increase in the cost of license tags, and the 1% bonus for our state retirees.

We are especially grateful for your support of the legislation related to the Community Services for Functionally Impaired Older Persons, and for the \$250,000 appropriated to the Commission on Aging to initiate this program of in-home services that will enable the frail elderly to remain in their own homes, avoiding institutionalization. This is a great start, but we need more money in order to help our state's elderly with this program. You will hear more on this later today.

We ask that you join us and our state's senior citizens organizations, such as AARP and the S.C. Federation of Older Americans, in a stronger than ever effort to obtain passage of the Probate Code Revision. We wholeheartedly agree with Governor Riley that our present system of laws related to death is a jumbled mass of rules that make probate

and estate administration too cumbersome and too expensive.

Our next request has to do with Alzheimer's Disease, a devastating illness that affects the cells of the brain. It is now recognized as the most common cause of severe intellectual impairments in older people. Presently, there is no treatment that can cure, reverse, or stop the progression of this disorder that causes serious confusion, memory loss, and inability to perform daily living activities.

The Commission on Aging has established the Advisory Committee on Alzheimer's Disease Initiatives to serve as an advocate for Alzheimer's Disease and Related Disorders victims and their families and to keep abreast of issues affecting them. The Committee also recommends legislation needed in the state to benefit victims and families and assists them with needed education and training activities.

The Committee has developed an issues paper to provide a focal point for legislative advocacy, and Dr. Sue Scally, Vice Chairman of the committee, will present the issues paper later today. We ask that you support this committee's recommendation.

Our final request is for your support of the proposed changes to the Commission on Aging Act. Presently, there are twelve Commission members ... two from each Congressional District. With the proposed changes, there would be seven Commissioners, one from each Congressional District and one at-large to be appointed by the Governor alone, without the advice and consent of the state Senate. This change would not only allow the Commission to more closely conform ^{to} the governing bodies of other state health and social service agencies, it would enable it to become a more efficient body. Currently, with twelve gubernatorial appointees, a five-member executive committee is given a great deal of the responsibility for the Commission's work between regular Commission meetings. A seven member Commission could take the total responsibility and meet as often as needed.

Under the proposal, each Commissioner would be appointed by the Governor with the advice and consent of the Senate, rather than the present gubernatorial appointment.

The proposal also calls for the Commission to elect its chairman, rather than the Governor appointing one, as is presently done.

We would appreciate your support on all our requests. Again, thank you for your previous efforts on behalf of older South Carolinians. We've come a long way and hope to go even further with your help.

Thank you.

Before his testimony, Mr. Harry Bryan asked Mr. James Rogers and Representative Pat Harris to stand. At this time he presented to both an award from Bethany College, "With Wings As Eagles" Institute. The awards had been given to the SC Commission on Aging by Mr. Perry Gresham, Director, when he spoke to the meeting in Greenville in May. Mr. Bryan also mentioned that the first one of these awards had been presented to Bob Hope in Orlando in January of 1983.

Following pictures Mr. Harry Bryan continued with his testimony.



SOUTH CAROLINA COMMISSION ON AGING

Presentation to General Assembly's Study Committee on Aging
10/2/85

Harry R. Bryan, Director

Thank you for all that this committee has done to help Older South Carolinians since it was established in 1969, and for all that you are going to do this year, and in the future. I wanted to take advantage of this opportunity to express that sincere word of thanks to you as it may be my last public opportunity to do so. Barring anything unforeseen, I plan to retire in June, and I do appreciate very much all that each of you, and this committee as a whole, have done for our state's older persons over the years, and the cooperation and support you have given to the Commission, and to me.

Now, before calling on Jim Dubs for a major part of our presentation, let me briefly mention a few items I think you should consider for legislative action this year.

Of course I strongly support all of the recommendations presented to you by our Chairman, Dr. Meadors, including the Uniform Probate Code and the proposed changes in the law establishing the Commission on Aging, and also final passage of the "Death with Dignity" legislation.

A special word of my own, now, about one of the modern "Plagues", Alzheimer's Disease (the other is AIDS). Dr. Robert Butler, former Director of the National Institute on Aging, is quoted in the August 12 issue of U.S. News and World Report as saying: "Nothing is more frightening to people than growing old, losing your mind, becoming totally dependent on others and being institutionalized - it's a living death."

Not nearly enough research is being done, and there needs to be more aid to victims of Alzheimer's Disease and their families, but your next three speakers are better qualified than I to speak on this "living death". I respectfully urge you to support their recommendations.

We have come a long way toward helping the frail elderly remain in their homes, where they prefer to be, and the least costly place for them to be; we have come a long way toward providing them the opportunity to live within the least restrictive environment possible, and toward maintaining individuality and personal freedom, for those who require nursing home care.

The \$250,000 appropriated to establish in-home services for frail older persons, regardless of income or need for institutionalization, is most appreciated. However it is, as you all know, only a beginning. We plan to present the guidelines for the use of those funds to our Commission in early December and begin providing services to the frail elderly with those dollars in January. When we get increased funding (the \$2.5 million we're requesting) we'll want to add some other services to the list, such as minor home repairs and home delivered meals on weekends. Help with payment for prescription drugs is a great need of those with incomes just above the Medicaid cap, and I urge you to support sound recommendations which might provide this assistance.

We desperately need the \$2.5 million to provide the home-delivered meals, medical transportation, homemakers, day care, and other services that will make an alternative to the nursing home a reality for many. The facts that these services will be coordinated with existing services and that a sliding fee scale for services will be used make this an effective and efficient approach to solving a serious problem that we have all faced or will have to face in the future. The trauma and expense of entering a nursing home or admitting a loved one, regardless of the tremendous job most of our nursing homes are doing, are dreaded by all of us. We ask your continuing help in this matter.

At this time I will call on our very capable Deputy Director to further elaborate on this need: Jim Dubs.

TESTIMONY PRESENTED TO THE
GENERAL ASSEMBLY STUDY COMMITTEE ON AGING
BY
JAMES D. DUBS, DEPUTY DIRECTOR
S. C. COMMISSION ON AGING
OCTOBER 2, 1985

MR. HARRIS, MEMBERS OF THE STUDY COMMITTEE ON AGING, I APPRECIATE THE OPPORTUNITY TO SPEAK TODAY ON THE NEED FOR A STATE PROGRAM OF COMMUNITY AND IN-HOME SERVICES FOR THE FRAIL ELDERLY.

HARRY BRYAN HAS ALREADY MENTIONED THE \$250,000 APPROPRIATED THIS YEAR. GUIDELINES ARE NOW BEING DEVELOPED ON THE USE OF THESE FUNDS AND THE MONEY WILL SOON BE PROVIDING SERVICES ON A LIMITED BASIS TO FRAIL OLDER PEOPLE.

HOWEVER, FOR THESE SERVICES TO BE OFFERED STATEWIDE, THE FULL \$2.5 MILLION REQUESTED IS NEEDED.

THE \$250,000 APPROPRIATED THIS YEAR IS A NON-RECURRING APPROPRIATION. IT WILL NOT AUTOMATICALLY BE APPROPRIATED FOR THE 1986-'87 FISCAL YEAR.

WE WERE DISAPPOINTED THAT THE BILL TO ESTABLISH THIS PROGRAM STALLED IN THE HOUSE LAST YEAR. HOWEVER, WE NOW RECOGNIZE THAT THERE WERE HONEST CONCERNS ABOUT ESTABLISHING THIS "NEW" PROGRAM AND FEEL IT IS OUR RESPONSIBILITY TO ADDRESS THESE CONCERNS. FIRST, THESE ARE NOT "NEW" SERVICES; I HOPE WE HAVE NOT GIVEN THAT IMPRESSION IN OUR ZEAL TO ADVOCATE FOR THIS NEW STATE-FUNDED PROGRAM. THE PROGRAM IS NEW, BUT NOT THE SERVICES.

THESE FUNDS (WITH OR WITHOUT A COMMUNITY SERVICES BILL) WOULD BE USED TO EXPAND SERVICES WITHIN THE STATE AND TO MAKE THEM AVAILABLE TO OLDER PERSONS ON THE BASIS OF NEED RATHER THAN INCOME.

THERE IS CONCERN THAT THESE SERVICES DUPLICATE COMMUNITY LONG TERM CARE (CLTC) SERVICES. NOT SO. THEY WOULD REACH TWO POPULATION GROUPS NOT ELIGIBLE FOR CLTC SERVICES: FIRST, PERSONS WHOSE INCOME OR RESOURCES EXCEED THE MEDICAID GUIDELINES; AND, SECOND, THOSE OLDER PERSONS WHO DESPERATELY NEED SERVICES BUT WHO ARE NOT QUITE ILL ENOUGH TO QUALIFY FOR MEDICAID NURSING HOME ADMISSION (A CRITERION FOR QUALIFYING FOR CLTC SERVICES).

STILL ANOTHER CONCERN WE HAVE HEARD IS THAT THIS PROGRAM COULD DEVELOP INTO A "BUDGET-BUSTER" LIKE FEDERAL PROGRAMS SUCH AS MEDICARE OR MEDICAID. AGAIN, NOT SO. THE FEDERAL "BUDGET-BUSTERS" ARE ENTITLEMENT PROGRAMS; I.E., ANYONE WHO MEETS THE ELIGIBILITY CRITERIA IS LEGALLY ENTITLED TO THE SERVICE. CONSEQUENTLY THE BUDGET MUST RISE TO THE DEMAND. PROGRAMS SUCH AS THE OLDER AMERICANS ACT AND THE SOCIAL SERVICE BLOCK GRANT, ON THE OTHER HAND, ARE NOT ENTITLEMENT PROGRAMS. THEY PROVIDE SERVICE ONLY TO THE EXTENT THAT FUNDS ARE AVAILABLE. THAT'S THE WAY WE SEE THIS PROGRAM, AS A MEANS TO EXPAND EXISTING SERVICES AND TO REACH PEOPLE NOT ELIGIBLE FOR SOME OF THE EXISTING PROGRAMS. ALSO, AS YOU WILL RECALL, OLDER PERSONS WILL PAY FOR SERVICES BASED ON THEIR INCOME, AND FEES GENERATED WILL FURTHER EXPAND THE AMOUNT OF SERVICES THAT CAN BE PROVIDED.

DR. ERIC PFEIFFER, DIRECTOR OF THE SUNCOAST GERONTOLOGY CENTER, HAS DEVELOPED A GRAPHIC MODEL WHICH ILLUSTRATES TRANSITIONS FROM ONE STATUS OF WELLNESS TO ANOTHER AS IT APPLIES TO OLDER PERSONS.

DR. PFEIFFER'S MODEL IS IN BLACK AND WHITE; I HAVE ADDED THE LOCAL COLOR.

THE RIGHT SIDE OF THE DIAGRAM REPRESENTS THE NON-POOR ELDERLY, WHILE THE LEFT REPRESENTS THE POOR ELDERLY. THE THREE BOXES ON EACH SIDE REPRESENT, FROM THE BOTTOM UP THE WELL, THE MODERATELY IMPAIRED AND THE SEVERELY IMPAIRED ELDERLY. THE OPENINGS, OR GATES AS DR. PFEIFFER CALLS THEM SHOW, WITH ARROWS, THE MOVEMENT FROM ONE STATUS TO ANOTHER. NOTE THAT THE ARROWS MOVING UPWARD ARE LARGER THAN THOSE COMING DOWN. THIS ILLUSTRATES THAT OLDER PERSONS TEND TO MOVE FROM BEING WELL TO BEING IMPAIRED RATHER THAN MOVE FROM IMPAIRMENT TO WELLNESS.

PLEASE ALSO NOTE THAT THE ARROWS FROM ONE SIDE TO THE OTHER GO ONLY IN ONE DIRECTION: FROM NON-POOR TO POOR. IT IS VERY UNLIKELY THAT A POOR OLDER PERSON WILL BECOME BETTER OFF FINANCIALLY.

YOU SEE THEN THAT LARGE NUMBERS OF OLDER PERSONS GRAVITATE TOWARD BEING MORE IMPAIRED AND POORER.

DR. PFEIFFER STRESSES THE NEED TO STEM THIS MOVEMENT AT ALL THE GATES. HE POINTS OUT THAT MOST EFFORTS AMONG STATES HAVE BEEN FOCUSED ON GATE A, MOVEMENT OF THE MODERATELY IMPAIRED POOR ELDERLY INTO MEDICAID NURSING HOME BEDS. HOWEVER, HE IS QUICK TO POINT OUT THAT IN FLORIDA ONLY 1/3 OF PERSONS WHO OCCUPY MEDICAID BEDS ENTERED THROUGH GATE A. STATES WITH WAIVER PROJECTS SUCH AS COMMUNITY LONG TERM CARE ARE CONDUCTING PRE-ADMISSION ASSESSMENTS, CERTIFICATION, AND DEVELOPING SERVICE PLANS TO OFFER AS ALTERNATIVES TO NURSING HOME CARE FOR MEDICAID CLIENTS. HOWEVER, 2/3'S OF FLORIDA'S MEDICAID NURSING HOME POPULATION ENTERED THROUGH GATE E. THAT IS,

THEY WERE PRIVATE PAY NURSING HOME PATIENTS WHO EXHAUSTED THEIR RESOURCES AND BECAME MEDICAID ELIGIBLE. AS DR. PFEIFFER PUTS IT, WE ARE TRYING TO STOP THE BLEEDING AT GATE A, WHILE THERE IS AN UNCONTROLLABLE HEMORRHAGE AT GATE E.

NOW, HOW DOES THAT RELATE TO OUR PROPOSED PROGRAM OF IN-HOME AND COMMUNITY SERVICES FOR THE FRAIL (OR FUNCTIONALLY IMPAIRED) ELDERLY? THAT'S WHERE MY COLORS ENTER THE PICTURE. THEY DON'T QUITE FIT DR. PFEIFFER'S MODEL; NOTE THAT THEY OVERLAP. ALSO, PLEASE BE AWARE THAT NEITHER HIS MODEL, NOR MY OVERLAYS, ARE TO SCALE IN RELATION TO NUMBERS OF OLDER PERSONS. WERE COLORS REPRESENTATIVE OF SIZE, THE GREEN AT THE BOTTOM, THE WELL ELDERLY, WOULD BE LARGEST. THE WHITE WOULD BE THE SMALLEST IN SOUTH CAROLINA. I HAVE SHOWN MEDICAID AS EXTENDING DOWN INTO COMMUNITY CARE, AND THAT, FOR MY PURPOSE IS IMPORTANT . . . THAT AREA REPRESENTS COMMUNITY LONG TERM CARE.

THE AREAS I HAVE SHOWN IN YELLOW REPRESENT THOSE OLDER PERSONS WE HOPE TO SERVE WITH THE FUNDS WE ARE REQUESTING. THEY INCLUDE THE POOR WHO ARE NOT IMPAIRED TO THE LEVEL THAT WOULD QUALIFY THEM FOR INSTITUTIONALIZATION AND THE BETTER-OFF WHO DON'T QUALIFY FOR OTHER PROGRAMS. I HAVE DELIBERATELY OVERLAPPED THE NURSING HOME LINE ON THE NON-POOR SIDE TO INDICATE SOME SEVERELY-IMPAIRED OLDER PERSONS MAY BE KEPT AT HOME WITH THESE SERVICES.

I WOULD LIKE TO CALL YOUR ATTENTION TO THE FACT THAT I ALSO SNEAKED THE COMMUNITY SERVICES YELLOW DOWN INTO THE WELL ELDERLY AREA. I WOULD HOPE THAT WE CAN PROVIDE, AT SOME POINT, PREVENTIVE OR EDUCATIONAL SERVICES TO KEEP OLDER PEOPLE WELL.

YOU ARE ALREADY AWARE OF THE TREMENDOUS INCREASES IN NUMBERS OF OLDER PERSONS PROJECTED OVER THE NEXT FEW DECADES, SO I SEE NO NEED TO GO OVER THEM WITH YOU.

IT IS SIMPLY IMPERATIVE THAT WE TRY TO KEEP OLDER PERSONS AT THEIR HIGHEST LEVEL OF WELLNESS, AT THE MOST APPROPRIATE AND LEAST EXPENSIVE LEVEL OF CARE. WE FEEL THAT \$2.5 MILLION FOR STATE FUNDED SERVICES WILL BE A MAJOR STEP IN MEETING THAT GOAL.

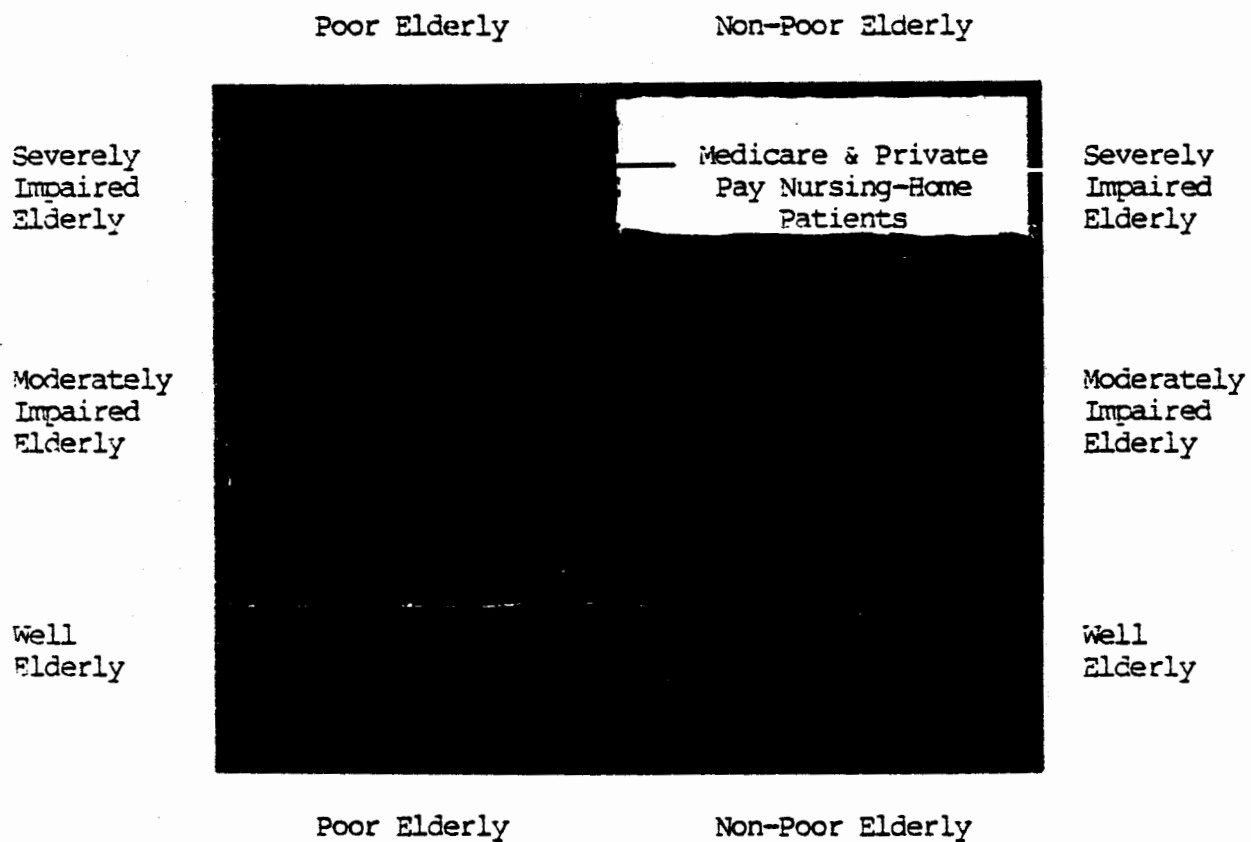
THANK YOU AGAIN FOR THE THE OPPORTUNITY TO MAKE THIS PRESENTATION. I WILL BE HAPPY TO (TRY TO) ANSWER ANY QUESTIONS YOU MAY HAVE.

Representative Blackwell asked if Mr. Dubs planned to do a demonstration project.

Mr. Dubs replied that they plan to make an award to each area agency with instructions to use in one county only.

Representative Blackwell's response was that \$25,000 for each county would not be able to do much good, but if the total amount was used for a demonstration project they would have more success in showing what can be done. If the pilot project showed good results then the Committee would not have a problem with expanding the program.

A MODEL OF TRANSITIONS*



*(Pfeiffer, Cairl, Henderson, 1983)

I would like to direct my remarks mainly to the people who are out in the audience. I know how Dave Waldrop feels and how informed Pat Harris, Peden McLeod and Dill Blackwell are because I have worked with them for a number of years. You sitting out there represent some 25+ organizations and in the years that I have worked in the health care field, I have been aware of the fact that we were going to start having some problems and how we are going to conduct ourselves in regards to the elderly. And that problem is getting to be a growing one.

But my concerns are that you people that represent these varied organizations do it on a voluntary basis which is very admirable and you do a good job with it in the cases I have been associated with you. And you devote a lot of time. Most of you are very intelligent people. What I would like to see you do is devote more time on a more collective basis.

In other words, instead of having the Federation of Older Americans, of which I serve on their board. I am vitally interested in what they are doing because I am interested in how we are going to take care of older Americans from now and a few years down the road because we are getting more and more of them. I thought we were still at 22% and Pat Harris tells me this morning we have escalated to 27% since last I checked. We are keeping people around longer through our research and development processes in the health care field. We are keeping them longer and healthier. Do not be misled by the fact that young people are going to take older people into their homes. We do not see that on the horizon. The Congress has been willing to talk about giving tax incentives for people who would keep their loved ones in the home. Well, do not be too surprised if you do not see a lot of that.

We have key organizations in place in South Carolina who are in the planning, processing and implementation processes including this Committee, the Health and Oversight Committee, the Senate Medical Affairs Committee and the Statewide Health Coordinating Council and more importantly where you are concerned, the Health Systems Agencies of which there are four in South Carolina. Those are agencies you should tie in with. If you come up here before this committee representing 15,000 or 20,000 people as opposed to one small organization, your voice is going to be heard vibrating off these walls. I hope you get my message.

TESTIMONY
PRESENTED TO
THE STATE OF SOUTH CAROLINA
BY
SUE L. SCALLY
CO-CHAIRPERSON
S.C. COMMISSION ON AGING
ADVISORY COMMITTEE ON ALZHEIMER'S DISEASE AND
RELATED DISORDERS INITIATIVES

Today I am representing a committee established by the S.C. Commission on Aging to advise the Commission on all activities related to Alzheimer's Disease and related disorders. Our functions are primarily advocacy, education and training, dissemination of information and assistance to family support groups.

The Advisory Committee has developed this issues paper to present a focal point for legislative advocacy in the South Carolina Legislature, as well as for advocacy with state agencies. The priorities developed are a reflection of the needs expressed by members of the Committee as an outgrowth of their personal and professional experience with Alzheimer's Disease (A.D.).

Alzheimer's Disease, a devastating illness that affects the cells of the brain, is now recognized as the most common cause of severe intellectual impairment in older individuals. Presently, there is no established treatment that can cure, reverse, or stop the progression of this disorder that causes serious confusion, memory loss, and inability to perform activities of daily living.

Although estimates vary, nationally A.D. affects between 5% and 10% of all people over age 65 and more than 20% of persons over age 80. Alzheimer's patients constitute 50-60% of the 1.3 million people in nursing homes, accounting for more than half of the \$25 to \$26 billion annually spent on such care. This disease will become more prevalent and take an even greater toll as our population continues to age.

The state and national governments must find solutions to the following issues:

I. Health Insurance

Although most Alzheimer's patients are elderly, Medicare pays little of the cost associated with caring for such persons. Consequently, private insurance designed to supplement Medicare also pays little or nothing.

Because Medicare is limited to skilled nursing care, the intermediate care more frequently required by A.D. patients is not covered. Likewise, the personal care required in the home (bathing, grooming, feeding) is left uncovered by Medicare. Thus, most patients must rely on private funds until these are exhausted and they become eligible for Medicaid.

Given the prolonged nature of the illness (often lasting ten to fifteen years), the cost of caring for an A.D. patient is staggering. There is almost no way for a family to be financially prepared or able to stretch

resources to cover such an extended and expensive illness. By some estimates, even a family with assets of \$350-400,000 will become impoverished.

It is therefore imperative that changes be made in private insurance to provide long term care insurance for non-acute, chronic illnesses, such as Alzheimer's, stroke-related disability, Parkinson's Disease, etc. Neither private finances nor public insurance can bear the burden of an increasing incidence of Alzheimer's Disease.

II. Tax Deductions

As noted above, the cost of caring for an Alzheimer patient can be devastating. Tax credits or deductions for such care would help offset part of the financial burden for families. This might include tax deductions for day care, homemaker or sitter services or for intermediate care costs in a nursing home. Currently, because these are not considered to be medical expenses, they provide no tax relief.

III. Nursing Homes and Residential Care Facilities

Most persons with Alzheimer's or related disorders will eventually be cared for in a nursing home and/or residential care facility. Thus, the issue of accessible and quality care is of paramount concern..

- A. Under accessibility, the Committee is concerned about the number of nursing homes available and their location. The current freeze on nursing home beds has created waiting lists and has made it difficult for the placement of their family member in close proximity to home. In addition, even when beds are available, A.D. patients may be turned away because of the special management problems related to demented patients.
- B. The monitoring of care provided in nursing homes and residential care facilities is of vital importance. Development of patient care standards (not just facility standards) is long past due: standards regarding bathing, dressing, feeding, privacy, etc. A re-consideration of staff-patient ratios is called for when care of demented patients is involved; also, other regulations should be examined in light of the special needs of demented persons (e.g., the need for waivers to permit locked doors to protect against wandering).

We commend the passage of the Patient Bill of Rights and urge its speedy implementation. While this is an important step forward, monitoring to ensure compliance will be critical.

In addition, there should be a sufficient number of ombudsmen with sufficient authority to ensure access by patients and family members and appropriate follow-up to complaint resolutions. The fear of retribution is a major deterrent to utilizing the grievance process.

IV. Availability of In-Home Services

With appropriate community support, it is often possible to maintain the A.D. patient at home until the last stages of the illness. This is generally more satisfactory to the family and patient and generally less expensive.

Expansion of respite services for the caregivers and personal care services for the patient may make the difference between keeping the person at home and institutionalization. The physical and emotional demands of Alzheimer's rapidly diminish the caregiver's energies and health; and without appropriate support, the caregiver may indeed become an additional victim of the illness.

V. Establishment of Alzheimer's Disease Register

The growth of Alzheimer's support groups in the state testifies to the increasing cry for help from Alzheimer families. There are now nine support groups in the state: only three years ago, there were none. However, the number of persons with Alzheimer's Disease in South Carolina is unknown; estimates vary from 24,000 to 30,000. To develop plans and services that are realistically founded, more information is needed about the incidence and distribution of A.D. in the state. To this end, the Advisory Committee recommends the immediate establishment of a state registry. Similar registers are now maintained for other diseases.

For your information, I have attached to my testimony a paper outlining the national action program of the Alzheimer's Disease and Related Disorders Association.

CONCLUSION:

President Reagan, in his proclamation of November 1983 as National Alzheimer's Disease Month, stated that: "The emotional, financial and social consequences of Alzheimer's disease are so devastating that it deserves special attention." With the increasing incidence of the disease, it will require a re-examination of our systems of health care and social services and a willingness to commit necessary resources. The Advisory Committee commends the South Carolina Commission on Aging for its initiative in establishing the Committee. We urge your careful consideration of the issues presented today.

Thank you for the opportunity to share these concerns.

10/02/85

Representative Blackwell asked Ms. Scally how much per patient costs would be and would the entire cost be a credit against state tax.

Ms. Scally stated that they have not drafted any specific legislation but have established a committee to study this issue.

Representative Blackwell asked Ms. Scally if she would be willing to discuss this with the Tax Commission.

Ms. Scally replied yes she would like to discuss this.

Dr. Parrish asked if the advisory committee was established through the Commission on Aging.

Ms. Scally said that the committee is composed of a wide variety (representatives from local aging service providers, regional area agencies, nursing home persons, family members, etc.)

Representative Harris asked what coverage these patients have.

Ms. Scally replied that most insurance policies cover only skilled nursing care. If interim care is needed there is no help. Day-to-day care for Alzheimer's Disease patients is not covered.



NATIONAL PROGRAM TO CONQUER
Alzheimer's Disease

Prepared by

March 1985



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March 1985

ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION

National Program to Conquer Alzheimer's Disease

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"Given the threshold blessing of longer lives, the important question then becomes how healthy, active, and independent our older years will be. Even as the proliferation of medical miracles and ever improving health care have been major contributing factors in this ongoing transformation of our nation 'profile', too many of our people still fall prey to serious illness. None is more terrifying and life altering for the elderly than Alzheimer's disease."

Margaret M. Heckler
Secretary, Department of
Health and Human Services
September 1984

I. STRENGTHENING SUPPORT FOR MEDICAL RESEARCH

"Recent advances in brain research have put us in the midst of the most exciting era since the dawn of the space age."

Michael Phelps, Ph.D.; UCLA
Wall Street Journal, 12/19/83

Although significant advances have been made in understanding the working of the human brain, the cause of Alzheimer's disease is still elusive. New hypotheses are being vigorously tested in a growing number of investigations. These studies are focusing on etiological factors as diverse as chemical deficiencies, immune dysfunction, slow viruses and unconnected agents, toxins, trauma and genetic abnormalities.

The number of unanswered questions is so great that the federal government must play a substantial role in helping to mount a strong and sustained research effort. The following areas are recommended as promising directions for future research:

* Etiology and Pathogenesis

- Support and enlarge research in order to enhance understanding of the cause(s) of the progression of Alzheimer's disease. Such research would include attention to the etiological impact of chemical deficiencies in the brain, advancing chronological age, genetic abnormalities, atypical transmissible agents, environmental toxins and trace metals, autoimmune dysfunction, and psychosocial trauma and stressors.
- Encourage existing brain tissue banks to include tissue from Alzheimer's disease patients and from age-matched controls; periodically review to ensure an adequate number of such facilities.
- Develop animal models of Alzheimer's disease with more precise neuropathologic and biochemical correlates.

* Diagnosis

- Develop international standardized diagnostic research criteria.
- Develop biological and/or behavioral markers for the early detection of Alzheimer's disease.
- Undertake longitudinal studies in order to document in a systematic fashion the progression of the disease.
- Examine cases of serious discrepancy between degree of cognitive deficit and extent of brain impairment.

* Clinical Course

- Develop longitudinal assessment instruments capable of reliably measuring behavioral and biological change over multiple points in time.
- Investigate factors that hasten or delay the progression of symptomatology.
- Examine individual differences and variability in severity, rate of deterioration, duration of illness and capacity for self-care.

* Treatment

- Develop new treatment agents for the cognitive and other impairments of Alzheimer's disease.
- Establish more sensitive measures of cognitive, affective, somatic, and other changes for use in drug outcome studies.
- Evaluate the influence of the environment on Alzheimer's disease patients and collect information regarding the range of behavioral plasticity in patients at different stages of the disease.

* Epidemiology

- Develop standardized diagnostic assessment for Alzheimer's disease that are suitable for use in field studies.
- Determine age-specific incidence and prevalence rates of Alzheimer's disease in diverse populations and study the course of illness.
- Assess a variety of possible risk factors that may be associated with the development of Alzheimer's disease.

II. PROVIDING FAIR AND EQUITABLE CONSIDERATION UNDER FEDERAL DISABILITY PROGRAMS

The Social Security Administration has national responsibility for the administration of both the Social Security Disability Program (Title II) and the newer Supplemental Security Income Program, or SSI (Title XVI). Title II provides coverage for cash benefits to those disabled workers, and their dependents, who have contributed to the social security trust fund through the FICA tax on their earnings. These individuals have an earned right to disability insurance benefits. Title XVI provides for a minimum income level for the needy aged, blind, and disabled who qualify because of financial need rather than an earned right.

Under both programs, the definition of disability is the same -- "an inability to engage in any substantial gainful activity by reason of a medically determinable physical or mental impairment which can be expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 months." The determination as to whether or not an applicant is disabled as defined by law is made by a special disability determination unit in each state.

Current policy is vague

The statutes authorizing disability benefits do not preclude benefit payments to individuals suffering from Alzheimer's disease. However, the guidelines used by claims examiners to determine eligibility are somewhat vague when it comes to Alzheimer's disease and related disorders.

One very typical example of the problem involves a 58 year old woman who was diagnosed with Alzheimer's disease in 1980. Last year, she was denied disability benefits even though the Social Security Administration noted that she has "...some difficulty in concentrating and remembering and an inability to travel by yourself."

The disease is not listed among those brain disorders specifically identified in the guidelines. At the present time a determination of disability due to Alzheimer's disease must be made under the "mental disorders" category. Unfortunately, the eligibility criteria under this category do not lend themselves to cases involving Alzheimer's disease. Furthermore, in some areas state laws prohibit the use of certain specific diagnostic tools needed to demonstrate deterioration in intellectual functioning.

The vagueness in regulations and guidelines has led to wide variations from state to state and an uneven policy towards individuals who have a rightful claim to benefits. In some states rulings have made it possible to determine most Alzheimer's patients are disabled, while in others, extremely strict rulings have made it almost impossible to find an Alzheimer's patient to be "significantly impaired".

Among other things, it seems apparent that the serious and debilitating nature of Alzheimer's disease -- information that is so readily available to scientists and many physicians -- is not being communicated to those who must make the critical, day-to-day eligibility determinations.

Recommendations

1. The federal regulations and guidelines used in evaluating disability claims should be amended so as to recognize the rights of individuals diagnosed as having Alzheimer's disease.
2. A mechanism should be established whereby the most current scientific information available to the National Institutes of Health and the National Institute of Mental Health is communicated to those responsible for administering disability programs.
3. Federal agencies, working together with medical and scientific community, should devise specific assessment tools that could be uniformly used by examining physicians.

III. MEETING LONG-TERM CARE NEEDS

Long-term care is a growing national concern. Yet, by and large, national public policy overlooks the most pressing needs of this segment of the population, including those individuals suffering from Alzheimer's disease.

The catastrophic costs of long-term care for Alzheimer's patients often are borne almost entirely by their families, since neither Medicare nor most private insurance plans provide coverage. Medicaid offers some assistance for nursing home costs, but only after families have spent down to poverty in order to qualify.

While the population of Alzheimer's patients is not exclusively aged (more than 60,000 victims are in their forties and fifties), the vast majority are over age 65 and in serious need of assistance, including -

- around-the-clock supervision
- medical assistance
- personal care (eating, bathing, dressing, toileting)
- mobility assistance
- household assistance (meal preparation, housekeeping)

While most families are likely to encounter difficulties coping with long-term medical care costs, those difficulties are far more pronounced for the elderly. Most frequently, the long-term care needs of an Alzheimer's victim arise at a time when the family's economic and social resources are dwindling -- oftentimes after savings, other assets, and pensions are nearly exhausted. Of course, the problems are particularly serious for the large number of victims who have no family or friends to care for them.

Compounding the problem for families is the fact that what little assistance is available is biased toward institutionalized care. The fact is that about two-thirds of the Alzheimer's victims with families are cared for in the home; only when the disease is in its final stages are families likely to turn to nursing homes for help. Even then, families of Alzheimer's victims are likely to encounter problems with access, as many nursing homes prefer short-stay, Medicare or privately insured patients.

Finally, the needs of families are virtually ignored by our system of social protections. No provision is made for the needs of the spouse who is caring for an Alzheimer's victim, including home health care, adult day care, and periodic respite care to help fortify the health and well-being of the care giver.

Given this myriad of problems, it is recommended that an integrated long-term continuum of care be provided for victims of Alzheimer's disease. Toward this end, the following actions are recommended:

Recommendations:

1. Medicare coverage should be extended to cover the costs associated with caring (at home or in a nursing home) for victims of Alzheimer's disease.
2. Greater emphasis should be placed on research studies and demonstrations to explore alternative health care delivery for Alzheimer's victims.
3. Victims, families, and care givers should be afforded a full range of home care services, including adult day care, respite care, homemaker, and nutrition services. (See also Section IV, Provision of Respite Care Services.)
4. Families and care givers should be permitted a tax deduction or refundable tax credit for the special added costs associated with caring for an Alzheimer's victim at home. (See also Section V, Incentives for Home Care.)
5. Private insurers should be encouraged to develop reasonable cost insurance plans that cover Alzheimer's disease.

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IV. PROVISION OF RESPITE CARE SERVICES TO FAMILIES

While most Alzheimer's families prefer to care for their loved one in the home, several studies* have reported on the problems experienced by the care giver; namely, emotional stress, loss of freedom, isolation, illness and financial strain. Given the demands for around-the-clock care and supervision, most family care givers are in desperate need of some relief, if only a chance to get away for a few hours.

Responding to the needs of the Alzheimer's families, Congress last year passed legislation which begins to address the issue of support services. Specifically, (a) the 1985 Labor-Health and Human Services Appropriations bill instructs the Administration on Aging to work with the Alzheimer's Disease and Related Disorders Association (ADRDA) and other groups in meeting local needs for respite care services, as well as develop a nationwide effort for providing respite; and (b) the Older Americans Act Amendments of 1984 sets aside funding to support local model projects to provide Alzheimer's disease families with a range of support services, including respite care, day care, and in-home health services.

Recommendation:

1. That the Administration on Aging launch a nationwide effort to meet the respite care needs of Alzheimer's families, and that the Alzheimer's Disease and Related Disorders Association be invited to participate in this effort.
2. That the Administration on Aging, in fiscal year 1986, begin to carry out the mandate of the 1984 Amendments by funding local model projects for respite care, day care, and in-home services.

* Archbold, 1982, 1981; Crossman, 1981; Fengler and Goodrich, 1979; Sanford 1975.

V. INCENTIVES FOR HOME CARE

The financial hardships of a family who has been touched by Alzheimer's disease is staggering. Around-the-clock care of an Alzheimer's victim can cost a family over \$30,000 per year. Many families virtually deplete their life savings, and eventually become dependent upon government programs for financial assistance.

The Alzheimer's Disease and Related Disorders Association believes that a national policy should be formulated which encourages families to care for their loved ones afflicted with Alzheimer's disease in the home. We find this to be the health care preference of a majority of our families. Moreover, such an approach offers a most effective way to reduce health care costs at the public level. (According to a 1984 analysis by the Education and Public Welfare Division of the Library of Congress, expenditures for nursing home costs are expected to grow from \$27.3 billion in 1982 to a level of \$67.1 billion by 1990.)

Recommendation:

That families be allowed a tax deduction or refundable tax credit for expenses, other than medical expenses, incurred for the caring of Alzheimer's victims in the home.

VI. ESTABLISHING A CONSISTENT POLICY TOWARDS VETERANS

The Veterans' Administration (VA) currently has no consistent policy with respect to veterans with Alzheimer's disease. This has resulted in uneven, some believe unfair, treatment of veterans. Some victims of the disease are admitted to VA medical facilities, while others are denied admission or referred to other state or private agencies. In some instances, veterans are being forced to leave VA facilities or are being "out-placed", thereby disrupting their care and placing even greater strain on the family.

The problem threatens to become even more serious as far greater numbers of veterans enter the vulnerable over-65 age bracket. (At present there are 3.3 million veterans age 65 and over; by 1995, that segment of the population will grow to over 8 million.)

Recommendations:

1. The Veterans' Administration should institute a fair and consistent national policy toward veterans with Alzheimer's disease. Guidelines governing the care and treatment of Alzheimer's patients are long overdue.
2. Local VA medical facilities should provide Alzheimer's disease screening, counseling, and treatment programs for veterans, their families, and care givers.
3. Recognizing that Alzheimer's disease can strike persons at a younger age, the eligibility requirements for veterans diagnosed with Alzheimer's disease should be lowered to age 50.
4. Model and/or innovative programs, e.g. adult day health care, should take into account the needs of a growing number of veterans with Alzheimer's disease and related disorders.
5. Support should be expanded for the VA's network of Geriatric Research, Education, and Clinical Centers (GRECC) program. Priority emphasis should be placed on activities involving Alzheimer's disease and related disorders.

VII. MEETING TRAINING NEEDS

Currently, very little training from either a research or a clinical perspective focuses exclusively on Alzheimer's disease.

Research

Despite increased awareness of the extent and burden of dementia in the elderly and despite very promising progress in research in recent years, considerable growth is needed in programs designed to train investigators and academic leaders in this field. A serious shortage of persons trained and committed to research and teaching in all aspects of dementia is well documented, and there are too few settings in the nation with sufficiently qualified faculty to train the needed investigators.

Recommendations:

1. Provide support for career development for faculty/investigators capable of proceeding more independently in education and research relevant to Alzheimer's disease.
2. Increase the number of National Research Services Awards in the field of neuroscience, in particular those focused on Alzheimer's disease.

Clinical Training

A growing understanding of improved treatment, care, and management of Alzheimer's disease requires a re-evaluation of clinical training needs and opportunities.

The specific areas requiring attention are:

- Development of a training curriculum specifically targeted to treating persons with Alzheimer's disease and to providing consultation to other service providers working with Alzheimer's disease patients.
- Attention to Alzheimer's disease in the basic training of clinical care providers potentially involved in the treatment of these patients (e.g., physicians, psychologists, nurses, social workers, etc.)
- Continuing education for those clinicians already in the field.
- Training focused on special population needs, such as the poor and minorities with Alzheimer's disease.

VIII. PROMOTING EDUCATION AND AWARENESS

There exists a fundamental need for education and understanding at all levels -- from the families and physicians to government officials, life insurance companies, and administrators of pension benefit funds. Only through greater awareness can we hope to change public attitudes toward Alzheimer's and other diseases of the mind.

Recommendations:

1. The federal government should continue to designate the month of November as National Alzheimer's Disease Awareness Month.
2. The Alzheimer's Disease and Related Disorders Association (ADRDA) will sponsor educational forums and disseminate information for both lay and professional people regarding the disease.
3. Throughout the year, ADRDA will continue to advise government agencies of the needs of those afflicted with the disease, as well as support research aimed at finding the cause and cure for Alzheimer's disease.
4. The ADRDA will continue to work with other national organizations where there is a shared concern for Alzheimer's victims and their families.

Honorable Members of the Committee on Aging:

On behalf of the Columbia Chapter for Alzheimer's Disease and Related Disorders, I wish to thank you for this opportunity to present further the needs of families within this State who are coping with Alzheimer's Disease. The Columbia Chapter endorses the views set forth in the issues paper presented by Dr. Sue Scally representing the Commission on Aging Statewide Task Force for Alzheimer's Disease.

As stated by Dr. Scally, Alzheimer's Disease is the 4th leading killer in the United States today, affecting some 3 million of our population. It is a slow, silent killer that destroys the brain of an individual. Usually affecting the memory first, it gradually reduces a person to a fetal positioned vegetable with life sustained by tube feeding. No cause, treatment nor preventive has been discovered, although extensive research is being pursued at leading centers across the country. The negative results lead us to realize the importance of more monies being allocated for research until an answer is found.

When Alzheimer's Disease strikes, normal family life ends. The strain of coping with a loved one who is gradually losing the ability to communicate, bathe, dress, walk and feed himself, becomes extremely frustrating and hard to bear. In short, life as a whole becomes a dreadful nightmare -- and as some have well stated "Alzheimer's Disease is a funeral that never ends."

Most Alzheimer's patients require constant care at least during the third or at best the fourth year of the illness. The irregularity of their sleep habits affords the caregiver very little rest. To avoid early burnout, some means of respite is necessary. The implementation of respite day care programs by the State would afford a solution to this problem as well as delay institutionalization in many cases. We heartily recommend that South Carolina follow the examples set by Florida, California, Illinois, Massachusetts, New Jersey, Pennsylvania, Rhode Island, etc. (See attachments).

We endorse wholeheartedly the issue raised with regard to health care insurance. We are all happy that through practicing better health habits and enjoying advanced medical knowledge the life span of the average American is being prolonged. However, this leads to the knowledge that individuals with otherwise healthy bodies will become victims of Alzheimer's Disease. When a couple has managed to put aside a few dollars to enjoy their golden years, it is an extremely devastating blow to have this disease strike one of them and wipe the savings out in a few years. This is happening again and again as AD takes its toll on older Americans. The spouse and/or children cannot provide the constant care required and have no alternative except to place

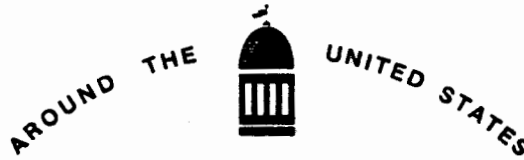
the loved one in a Nursing Home. It is our contention that the private insurance provider would bear no greater risk underwriting long-term care for AD than for cancer, heart disease, etc. The Middle Income Family has the right to this protection against bankruptcy. Private carriers must be mandated by State legislation to include long-term care for the Alzheimer's Disease patient. At present no carriers make provisions for long-term care in skilled care facilities. This situation bears studying and remedied. We urge this Committee to do so and make recommendations to the effect.

When Nursing Home placement becomes necessary, we often hear that facilities are not equipped to care for the AD patient. The reasons given are that they sometimes wander or become belligerent. We believe that a licensed facility in this State should be mandated to render the care needed by any patient without regard to disease. With the incidence of Alzheimer's rapidly increasing, special units staffed by persons aware of the unique needs of these patients are needed. Let me remind you that usually long before the need for placement occurs, AD victims lose the ability to ask for a drink of water and few are still able to feed themselves. This means that the family is extremely conscious of the care administered after placement and feel they have the right to ask that the necessary care be given. We wish to retain a good relationship with the Nursing Home Association because we realize that AD families will be more and more dependent upon them. The State Ombudsmen Program offers excellent means to resolving issues between the family and Nursing Home, yet many times negotiations get bogged down while the patient's needs continue and the family's agitation increases. We urge you to implement measures that will ensure the timely resolutions sought. We are also aware that a Procedures Care Manual exists, but adherence to the rules must be enforced for the benefit of the AD patient.

My husband was diagnosed in 1974 at the age of 49 and died in 1984 just before his 59th birthday. He was tube-fed for more than a year. I know too well the emotional frustration and devastation that Alzheimer's Disease brings to the family. To quote our President again, "The emotional, financial and social consequences of AD are so devastating that it deserves special attention." I wish to add that the rising incidence of the disease demands that it be given special attention; not only at the National level but at the State level also. NO ONE IS IMMUNE; in fact every one of us here today is a prime candidate. We are extremely grateful to Congressman Butler Derrick (Democrat) of the third district, for introducing the bill this year designating November as National Alzheimer's Disease Awareness Month.

The bill passed both the house and senate and was signed by the President. The entire South Carolina delegation supported it. Other legislation is pending at the national level to aid AD victims and their families; however, if passed, it will be a long time before any impact will be realized at the local level. We urge this Committee to take a close look at the ravages of this disease within South Carolina, to consider the 30,000 + victims, and begin the implementation of programs that will benefit them and their families. Many states have already implemented tax deductions for the care of AD victims, respite day care programs, required insurance language to include long-term care for Alzheimer's Disease, etc. (See attachments). We urge you today to recognize and relate to the growing need for these and similar services for the citizens of South Carolina.

Advocacy update



Preface: This is a preliminary listing of AD-related legislation introduced during the early 1985 sessions of the California and Illinois legislatures. It is intended to acquaint you with the types of bills being considered in these two states - and others - but does not imply that they have become laws in either state. An updated report should be available within three months, after the Governors have acted upon the bills submitted to them by both chambers of their legislatures.

CALIFORNIA

SB 173: Respite Care Service. Appropriates \$1 million for demonstration projects for respite care services. Department of Aging would administer the program and choose three grantees to operate programs for services to the frail, elderly, and functionally impaired persons and their care-givers, both in and out of home.

SB 421: Wills. Establishes specific presumption that a person is of unsound mind and cannot make a will if the person suffers from chronic mental unsoundness characterized by delusion or hallucinations.

SB 431: Aging Adult Day Health Care. Appropriates \$1.5 million for the existing adult day health care program administered by the Department of Aging. Increases the amount available to each project from \$50,000 to \$100,000. Establishes guidelines for local adult day health planning councils. Gives preference to centers serving a high Medi-Cal population.

SB 1113: Alzheimer's Disease. Appropriates \$1 million to the Department of Health Services to administer grants on research into the diagnosis, causes, treatment, and prevention of Alzheimer's Disease. Specifies guidelines for the awarding of grants. Also, requires the Health and Welfare Agency to establish an interagency committee to provide for the coordination and oversight of programs related to Alzheimer's Disease.

CALIFORNIA (continued)

AB 987: Medi-Cal eligibility. Revises law regarding eligibility and share of costs for the medically needy residing in skilled nursing homes and intermediate care facilities. Allows the non-institutionalized spouse to keep community property interest in a house and income previously considered when determining eligibility. Sponsored by the Legal Aid Society of Alameda County, this legislation is designed to ameliorate the problem of couples having to "spend down" income and assets or sell a jointly-owned home so that the institutionalized spouse is eligible for Medi-Cal, often leaving the remaining family with insufficient resources to cover their own needs.

AB 999: Alzheimer's hospitals. Establishes a 3-year demonstration project for Alzheimer's hospitals to be administered by the Department of Health Services. The model hospitals shall combine traditional programs with specialized strategies and interventions appropriate to meet the special needs of individuals afflicted with Alzheimer's Disease or related dementias, their caregivers, and their families. Applicants for the projects shall finance the operation but may apply for any state and federal funds available for Alzheimer's Disease programs or other appropriate purposes.

AB 1305: Alzheimer's Disease - respite care services. Requires the Secretary of Health and Welfare to issue a request for proposal of a study to determine the feasibility of insurance coverage for respite care services for patients with Alzheimer's Disease in order to maintain patients in the home as long as possible. Findings due by January 1, 1987. Appropriates \$75,000 for the study.

AB 1344: Income tax credits for health maintenance costs. Modifies Senator Rosenthal's legislation of last year (AB 1823) which attempted to gain tax deduction for families incurring costs in maintaining AD patients. This bill grants tax credits for health maintenance costs for any infirm and elderly adults living in the taxpayer's home in lieu of entering a nursing home.

AB 1687: Respite care program. Requires the Department of Aging to work with the Department of Health and Welfare to develop programs for the provision of both in-home and out-of-home respite care services to aged, blind and disabled persons.

AB 2202: Elderly persons - respite care. Provides for respite care services for elderly persons over 65 years of age who reside with a family but are at risk of institutionalization. Developed in cooperation with the Republican Caucus and the Health and Welfare Agency.

AB 2202: Tax credits for home health care. Authorizes tax credit for certain taxpayers who pay home health care costs or who personally provide home health care services for qualifying individuals afflicted with Alzheimer's Disease or related disorders. Requires physician's diagnosis. Limits credit to a percentage of costs incurred, and various limits apply.

ILLINOIS

HB 301: Creates the Alzheimer's Disease Treatment Assistance Act. Authorizes the Department of Public Health to award grants to postsecondary higher education institutions having medical centers or affiliation with medical centers for the purpose of establishing Alzheimer's Disease diagnostic and treatment centers. Specifies the criteria for awarding the grants and the purposes for which the grants may be used. Requires the Department to file an annual report with the General Assembly concerning the progress of the grant program.

HB 302: Amends the Public Aid Code. Provides that property held by a spouse pursuant to an equal division of marital property or transfer of interest in a home shall not be considered in determining a person's eligibility for medical assistance.

HB 303: Amends the Civil Administrative Code. Creates within the Department of Public Health an Alzheimer's Disease Task Force consisting of 11 members appointed by the Governor and the legislative leaders. Requires the Task Force to provide guidance to various State agencies having jurisdiction over health or medical assistance programs in regard to how those programs may more effectively serve the specific needs of the victims of Alzheimer's Disease and related disorders. Requires the Task Force to sponsor a Statewide conference on Alzheimer's Disease within one year after the effective date of this amendatory Act.

HB 304: Amends the Act on the Aging. Authorizes the Department on Aging to administer 3-year pilot project grants for the provision of various services for victims of Alzheimer's Disease.

HB 305: Creates the Alzheimer's Disease Reporting Act. Requires physicians and other persons employed by hospitals, nursing care facilities, clinics and other facilities to report any diagnosis or discovery of Alzheimer's Disease to the Department of Public Health. Authorizes the Department to release the information contained in the reports to persons and organizations seeking such information for legitimate health-related research purposes. Requires any person obtaining information from the Department to agree in writing to maintain the confidentiality of the identities of individual patients.

HB 306: Amends the Civil Administrative Code. Creates a task force for the study of long-term insurance within the Department of Insurance. Provides for 7 members to be appointed by the Governor and 3 members appointed by each of the Speaker of the House of Representatives and President of the Senate. Requires the task force to study the potential for private health insurance for long-term care for the elderly and to report to the governor and General Assembly no later than March 1, 1986.

HB 307: Amends the Nursing Home Care Reform Act. Requires long-term care facilities to conduct a physical and mental examination of a resident prior to or immediately following his admission to the facility in order to ascertain whether or not he suffers from Alzheimer's Disease or any other medical condition requiring specialized care. Requires the facilities to provide specialized care and services to any resident found to suffer from Alzheimer's Disease or other medical condition requiring specialized care.

ILLINOIS (continued)

SB 062: Creates the Alzheimer's Disease Research Act and amends the Illinois Income Tax and the State Finance Act. Creates the AD Research Fund in the State Treasury, monies of which may be appropriated by the General Assembly to the Dept. of Public Health for Alzheimer's Disease research grants. Provides for a voluntary check-off income tax system for individuals to contribute part of their tax refund to the fund.

SB 384: Amends the Respite Demonstration Program Act to extend its application to victims of Alzheimer's Disease.

SB 385: (Senate version of House bill HB 303)

SB 386: (Senate version of House bill HB 305)

SB 387: The sum of \$200,000, or so much thereof as may be necessary, is appropriated to the Department of Public Health for grants to qualified institutions as defined by the Alzheimer's Disease Assistance Act.

SB 388: Creates the Alzheimer's Disease Assistance Act. Authorizes the Department of Public Health to award grants to postsecondary higher educational institutions with medical centers for the purpose of establishing Alzheimer's Disease diagnostic and treatment centers. Also authorizes the Department to award grants for research aimed at finding a cure for Alzheimer's Disease. Requires the Department to file an annual report with the General Assembly concerning the progress of the grant program.

*SB 389: Amends the Illinois Insurance Code to require all policies of accident and health insurance issued in this State to include coverage for the care and treatment of Alzheimer's Disease, including coverage for hospital, nursing, surgical and medical expenses incurred in the care and treatment of Alzheimer's Disease. Also provides that such policies shall include disability income protection for insureds who suffer from Alzheimer's Disease.

SB 390: (Senate version of House bill HB 307)

SB 391: Amends Act in relation to rehabilitation of disabled persons. Includes persons who have Alzheimer's Disease in the definition of "disabled persons."

SB 392: Amends the Public Aid Code. Permits the Department of Public Aid to determine the feasibility of authorizing medical assistance payments for the diagnosis and treatment of Alzheimer's Disease.

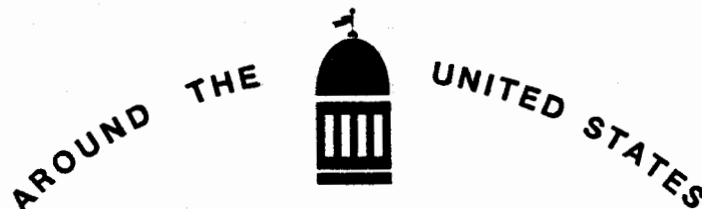
*Note: We have been informed that all of the above Illinois bills were passed in their respective houses, with the exception of SB 389.



Advocacy update

No. 13

July 31, 1985



Since Congress will be in recess from August 3rd to September 4th, we have taken this opportunity to compile a summary/overview which highlights this year's state-level legislative activities. While state AD Task Forces are an important accomplishment, please notice that tangible legislation has been introduced concurrently in several states.

Al Garfield,
Editor

California

(See Insert for detailed recap)

Connecticut

Committee Bill No. 582 - An act establishing a Task Force to study the needs of persons suffering from Alzheimer's Disease. (Passed)

Committee Bill No. 487 - To establish a state registry for the reporting of AD, within the Department of Health Services.

Florida

Two bills (HB 77 and SB 121), already signed by the Governor, include the following provisions:

- A trust fund to collect and distribute private donations for AD research.
 - Memory disorder clinics at Florida's three medical schools -- Universities of Miami, South Florida, and Florida.
 - An unspecified number of temporary, at-home care facilities when a spouse or guardian is away.
 - Three specialized day-care centers in conjunction with AD research programs.
 - An AD Advisory Committee to help coordinate the various programs.
- (Clark/Meek)

Georgia

Various state government agencies and departments, health organizations, ADRA groups, etc. were invited to an organizational meeting scheduled for July 9th. The ADRA-Atlanta Chapter and the Georgia Dept. of Human Resources will make a joint statewide study of the needs and problems associated with AD. These are first steps in the direction of developing a state public and private focus on AD, prior to an anticipated legislative initiative.

Hawaii

H.B. 780 - Appropriates over \$50,000. for a grant-in-aid to Kauai County Office of Elderly Affairs for the operation of an AD Day Care Center.

H.B. 1280 - Creates a pilot AD respite care program and appropriates approximately \$25,000. for this purpose. (The program began on July 1st and families are already receiving respite services).

Illinois

(See Insert for detailed recap)

Kansas

Senate Concurrent Resolution No. 1618 established an AD Task Force, under the direction of the state's Secretary of Aging, and required a report of findings and recommendations to the Governor and the Legislature before January 10, 1986. During the recent first meeting of the Task Force, a Mission and Duties/Issues Statement was distributed to its members. (Copies of the Resolution and the Mission Statement are available, upon written request, from Al Garfield c/o ADRDA National Office).

Maryland

Governor Hughes established an AD Task Force in January 1984, recognizing that the disease would become more common and take a greater toll as the state's aging population continues to grow. The Task Force was asked to submit a report to the Governor and the General Assembly by July 1985.

Massachusetts

On July 8th, the Governor's Committee on Alzheimer's Disease presented its findings to Governor Dukakis. The Executive Summary report includes the following recommendations:

- (1) Improved funding of long-term care through a combination of Medicare, private insurance and continued family contributions.
- (2) Changes in laws and regulations affecting those with Alzheimer's Disease.
- (3) Expansion of current state programs, such as day care and home care with a focus on the care of those with Alzheimer's Disease.
- (4) State record-keeping to determine how many citizens with Alzheimer's Disease are now being served through various systems, so that care may be both improved and made more cost effective.
- (5) A series of demonstration projects to determine how quality care of those with Alzheimer's Disease might best be implemented.

The legislature has already responded to these recommendations by providing funds to implement two of them. \$2 million dollars was provided to aid in the cost of respite care and \$375,000 dollars was provided for the establishment of a demonstration institutional program.

Senate bill No. 1043 is an act providing for the inclusion of custodial or nursing home care costs in health insurance policies, for persons with AD.

Michigan

Three tax credit bills have been introduced which are designed to reduce the financial burden on persons providing in-home care for ill, frail and impaired older persons. (Faxen: SB 150 - SB 283 - SB 306)

Minnesota

A 15-member Department of Human Services Task Force is directed to determine the needs of persons with brain impairments and their families and to develop a model continuum of care to meet those needs in a cost-effective manner. (S.F. No. 966)

The Omnibus Health and Human Services Bill includes a provision for removal of brains during an autopsy, for the purpose of Alzheimer's research.

Missouri

An AD legislative initiative is now underway. The House of Representatives has scheduled statewide hearings to ascertain the needs of victims and their families, prior to the drafting of legislation.

New Jersey

Assembly bill No. 3194 (Paterniti, Walker, Pelly, Vainieri) is an act establishing an AD day care center program.

The NJ Commission studying AD has called for the establishment of a \$3.8 million program, including adult day care, a university-based diagnostic center, improved professional education, development of a center to link victims/families with appropriate services and programs, and a statewide resource directory.

A \$500,000. appropriation for the Institute of Alzheimer's Disease and Related Disorders at Rutgers Medical School has been approved, we are told.

New York

A.1869 - An act authorizing research as to the cause, treatment and cure of AD, with an appropriation for that purpose. (Connelly)

A.5433 - An act to amend the mental hygiene law, in relation to requiring the Commissioner of Mental Health and the Commissioner of Health to develop a program for respite services for victims of AD, with an appropriation for that purpose. (Connelly)

S.1206 - Provides for respite services, similar to above Assembly bill. (Tully)

Ohio

A family member stirred State Senator Dave Hobson's interest in the problems surrounding the care of an AD patient. He was further enlightened, when he attended a support group meeting. As Chairman of the Health, Human Services and Aging Committee, he now plans to introduce legislation and schedule hearings during the summer/fall session. The bills to be drafted will address the needs regarding respite, day care, etc. in a comprehensive "package."

In the meanwhile, ADRDA's affiliated groups in the state are organizing a coordinated, joint advocacy program.

Pennsylvania

SB 5 - Protection of the Elderly Act appropriates \$2 million for protection of abused, neglected, exploited or abandoned elderly. Establishes a statewide reporting and investigative system.

(Loeper)

HB 460 - In-Home and Community Services Act requires the Department of Aging to provide assessment of individuals applying for a nursing home care and to provide community alternatives. Appropriates \$25 million from the lottery. (Kukovich)

SR 29 - Establishes a select committee to investigate the need for a statewide program focusing on issues involving children of aging parents.

SB 725 - Adds provisions relating to guardians of incompetents. (Sens, Fisher, and O'Pake)

SB 862 - Appropriates \$50,000 to the Department of Aging for an Alzheimer's Disease Task Force. (Sens, Zemprelli, and Fisher)

SB 863 - Provides for Department of Health research into Alzheimer's Disease. (Sens, Zemprelli, and Fisher)

HB 704 - Domestic Assistance for the Elderly Act establishes a program of limited domestic service for certain elderly or handicapped people. (Harper and Herman)

In his budget for FY 1985-86, Governor Thornburg has included an appropriation for \$500,000. as an Alzheimer's initiative; details not finalized.

Rhode Island

S.0823 - "The Department of Elderly Affairs shall mobilize the human, physical, and financial resources available to plan, develop, and implement innovative programs to ensure the dignity and independence of elderly persons, including.....a long-term care program." (Sasso)

Texas

HCR 88 is a Concurrent Resolution which recognizes that AD is a pervasive health problem of deep concern to the citizens of Texas and expresses full support of the Texas Department of Health in developing supportive and educational programs to help patients, their families, and nursing homes. It encourages the TDH to continue its efforts to organize and develop an Alzheimer's network composed of associations, family members, and other concerned individuals to deal with this problem.

Virginia

Earlier this year, the General Assembly overwhelmingly voted in favor of HJR 309, a measure establishing a Commission on AD and related disorders. Members of the Commission are scheduled to attend an initial meeting on August 2nd. Included in the bill is a recommendation for a study of the concept of a network of regional dementia centers.

Washington

The Governor has signed a bill which prohibits medicaid discrimination in nursing homes. (We are waiting for a copy of this measure, which will contain the bill number and more detailed information).

Wisconsin

State Senator Russ Feingold, Chairman of the Aging Committee, spearheaded an AD legislative initiative in January. Since that time, several proposals and the final report of the Wisconsin Task Force on AD and Other Dementias have been drafted. Assembly Bill 85 spells out the various services to be provided under the act and the appropriations to be allocated for funding the programs. (We are waiting for updates on the bills and the final Task Force report).

Dr. Parrish stated that the estimated 30,000 victims was conservative.

Representative Harris suggested that the Department of Mental Health could probably fund an increase to provide a facility. He stated that the Committee would do more checking to see if a facility could come under the Department of Mental Health.

PUBLIC HEARING BY THE JOINT LEGISLATIVE STUDY COMMITTEE ON
AGING

OCTOBER 2, 1985

TESTIMONY

OF

CHARLES N. STILL, M.D.

DIRECTOR, C.M. TUCKER JR. HUMAN RESOURCES CENTER

AND DEPUTY COMMISSIONER, LONG TERM CARE DIVISION

SOUTH CAROLINA DEPARTMENT OF MENTAL HEALTH

Mr. Chairman, honorable members of the Joint Legislative Study Committee on Aging, ladies and gentlemen - as a home grown South Carolinian, I deeply appreciate the privilege of speaking for the first time before this distinguished group. When I joined the Faculty of the William S. Hall Psychiatric Institute in July, 1965, there was only one standard of institutional care in the Department of Mental Health - acute psychiatric hospital care. But with the vision of men like William S. Hall and C.M. Tucker, Jr., and the collective wisdom of the General Assembly, guided by the foresight of the Joint Legislative Study Committee on Aging, South Carolina has become a national leader in long term care during the last 20 years.

Though neither the largest nor the most affluent Southern State, South Carolina today stands beside Virginia in having the largest number of JCAH - accredited nursing homes in the South. Moreover, the South Carolina Community Long Term Care Project has

brought national recognition as the only one of 13 demonstration projects which have produced a cost-effective alternative to nursing home care.

In contrast, the significant accomplishments of the Department of Mental Health in the field of Long Term Care have been largely overlooked.

In March 1969, plans were formulated for a Long Term Care Facility of 150 beds "to approximate the home atmosphere as closely as possible...(to) provide skilled nursing care for former mental hospital patients for whom no other alternative can be found.... The facility will be a model and a training center for other existing and projected nursing homes. Training will be offered to existing and prospective nursing home personnel in the proper management of the.....patients.....served. Patients will be referred to the facility by the medical staffs of the State's mental hospitals. Reciprocal agreements with community nursing homes will be sought.."

In June 1970, the Department of Mental Health opened this 150-bed facility as the John M. Fewell Pavilion; simultaneously the Long Term Care Facilities Division was established under the provisions of Section 32-920.1 of the South Carolina Code of Laws. In April 1971, another 150-bed Long-Term Care facility opened as the E. Roy Stone, Jr. Veterans Pavilion, also under the jurisdiction of the Mental Health Commission. Both these

pavilions and their 62-acre campus were dedicated as the C.M. Tucker Jr. Human Resources Center in February 1973. Ten years later, with no additional operating funds, the Frank L. Roddey Pavilion received its first patients on February 28, 1983, doubling Tucker Center's total capacity to 608 beds. Tucker Center is today the largest nursing home in South Carolina, and one of the largest in the South. Despite its large size, Tucker Center maintains high quality standards for patient care, evidenced by JCAH Accreditations, DHEC Licensure/Certification and VA approval.

Under the Code of Federal Regulations, the Nursing Service Director is responsible for multi-disciplinary patient care planning in Long Term Care Facilities. Our Nursing assistants, called Medical Health Specialists, are the principal direct caregivers at Tucker Center.

As the Teaching Nursing Home of the Department of Mental Health, Tucker Center emphasizes practical on-the-job training for all personnel, supplemented by Continuing Education programs from South Carolina ETV's Health Care Network as well as Staff Development presentations. Students, Residents and Fellows are welcomed each year in Nursing, Pastoral Care, Psychiatry and Social Work. As an example, more than 300 USC Senior Baccalaureate Nursing Students have received hands-on-training at Tucker Center, which has become South Carolina's first learning

laboratory in Long Term Care. So far, all this has been accomplished without the expenditure of additional State dollars.

During its entire 15-year history, Tucker Center has operated at virtually full occupancy with admission policies which are distinct and different from those of the Division of Psychiatric Hospital Services. Patients who are accepted for admission to Tucker Center are primarily in need of long-term skilled or intermediate nursing care under medical supervision for physical and/or mental disabilities associated with underlying medical or neurological disorders. Patients with known psychiatric disorders are admitted only if the patient's behavior does not endanger the patient or others. Even so, the majority of admissions to Tucker Center come from other facilities of the Department of Mental Health. The remainder come from the W.J. Bryan Dorn VA Hospital and other general hospitals. Medicaid-eligible applicants must be certified as to the need for nursing home admission and the appropriate level of care by the Community Long Term Care Program. Those patients who are found to require care and treatment beyond Tucker Center's capabilities are discharged to the nearest facility which is appropriate to meet the patient's identified needs.

Currently, Tucker Center has 458 Intermediate Care Facility beds, 100 Skilled Nursing Facility beds, and 50 Dually Certified beds.

In July 1981 an Admissions Evaluation Committee was established to evaluate applicants for admission, as well as candidates for discharge.

Despite our best efforts to accept all applicants judged appropriate for admission, all these beds are in such demand that most applicants must wait for weeks or months before a suitable bed becomes available.

During FY 1984-85, Tucker Center processed 513 admissions, 470 discharges and 29 deaths, providing 211,400 patient days of care at an average cost of \$45.18 per patient day. Please note that this cost includes 24 hour nursing care; room and board; all medications; rehabilitation, activity and social services; and medical care by a full-time attending physician. Those who believe that nursing homes are too costly should reconsider the ten to twenty-fold greater cost of a stay in an acute general hospital. For the ever-increasing numbers of the frail elderly, the nursing home is clearly the most cost-effective placement for those who need around-the-clock care. As Dr. Eric Pfeiffer has observed, "The cheapest form of long-term care is a funeral". I believe you will agree we can and must do more for older South Carolinians who need our help.

When I first arrived in Columbia, I was invited in August 1965 to speak to the Columbia Medical Society. I chose "Newer Concepts of Alzheimer's Disease". There were no questions from the

audience, who were ready to go home after a long and tiring Monday. Today, there are more questions than answers on Alzheimer's Disease, which has become the Gray Plague of the Twentieth Century. Tucker Center currently provides care for 275 patients with Alzheimer's Disease, mostly in the late stages. The risk for Alzheimer's Disease rises with age, from about 5% at age 65 to more than 20% at age 80. Women are at greater risk at all ages.

Alzheimer's Disease is the number one diagnosis at Tucker Center and in other nursing homes across the United States where Alzheimer's Disease victims occupy about half of the 1,400,000 beds in 19,000 nursing homes. Total health care costs for Alzheimer's Disease are projected to rise from \$26 billion in 1983 to \$750 billion by the year 2030, when more than 50 million Americans will be over age 65. Before this prophecy comes to pass, drastic measures will be needed to manage an overwhelming economic burden if legalized euthanasia and suicide are to be avoided.

Because of the irreversible and progressive effects of Alzheimer's Disease in the human brain, I do not believe that we can reasonably expect effective treatment to be developed before the year 2000, when South Carolina projects a population of 484,000 citizens over age 65. If only 10% develop Alzheimer's Disease, 48,400 beds must be found, either at home or in an institutional setting. Either way, caregivers must be trained to

cope with the progressive deterioration of memory, language, recognition and activities of daily living which occurs in Alzheimer's Disease.

Tucker Center is now working with the South Carolina Gerontology Center to develop an ICF-Alzheimer Unit based on the ICF-Mental Retardation facilities of VOCA, a privately owned company based in Ohio. If funded, this project could serve as a model for ICF-Alzheimer units across the country.

We must act now to train adequate numbers of caregivers, before a greater deluge of Alzheimer's Disease falls upon us. Whether caregivers are to work in the home or in the nursing home, there is no substitute for the hands-on experience a Teaching Nursing Home like Tucker Center can provide.

We are ready to join hands with you in carrying the burden of Alzheimer's Disease for those who can no longer bear the heavy load. With God's help, we surely must succeed.

Thank you very much.

Charles N. Still, M.D.

October 2, 1985

Director

Representative Harris asked Dr. Still to bring this same topic to the Mental Health Committee meeting on October 9th.

Dr. Still said he would be honored to attend.

Mr. Chairman, members of the committee, thank you for allowing me to present a few of my concerns to you.

As you are aware, the Ombudsman Office receives many calls for assistance each year; however, one of the frequent requests concerns the lack of funds to buy drugs. The citizens who are in the most need are those whose income is a few dollars over the SSI standard payment amount. By having an income of \$345.00 or more, an individual is not eligible for an SSI payment or Medicaid - which means there is no help for drugs. This individual has to make some very hard decisions, such as, do I pay my electric bill or do I buy my drugs, or what items of food can I do without, or how do I pay my taxes to keep my home? These are real everyday decisions for these people. I would hope that somewhere in the budget process you could appropriate funds to assist with this most critical need.

Another request that comes to our office is that there is a lack of physicians who will accept Medicaid or Medicare as payment in full for their services. This is especially true for those patients who are in nursing homes. I have received two letters within the past two weeks which state that the physician will not accept Medicaid payments or that no physician will serve the nursing home. It would appear that one of the reasons is that the payment is very low for the paper work involved.

When a physician refuses to accept Medicaid as payment, the patient must pay for these physician visits from his/her personal needs allowance. Patients also must use their personal needs allowance of \$25.00 to pay for drugs and other medical services. This, of course, is clearly against federal regulations, Section 435.725, which states that personal

needs funds are prohibited from being used for medical or remedial care. This is a common practice in many of the homes. There was a class action suit in California to bring the state into compliance; the decision was in favor of the nursing home patients. I would hope that we would take the necessary administrative steps to correct the situation before a similar suit is brought here in South Carolina. The Health and Human Services Finance Commission has had this brought to their attention and are currently studying this matter.

One of the more important issues that I would like to discuss is that of Medicaid discrimination. Medicaid recipients are treated like second class citizens many times. The area that my office receives the most calls concerns nursing home admissions. There are several ways to discriminate against a Medicaid recipient. The two most prevalent are 1) being denied admission when a home has empty beds or 2) to enter a home as a private pay patient and then be discharged when their personal funds have been exhausted.

Let me explain the problem as I see it. A nursing home will have all of their beds certified for both Medicare and Medicaid. However, the Medicaid patient does not have the same opportunity to be admitted as the private pay patient. The reason is fairly simple. The home can charge the private patient a higher rate and I have no problems with private enterprise. I do have a problem with a home suggesting that the Medicaid and private pay patient have equal access. The nursing home is certainly implying by having all of their beds certified for Medicaid that both private pay and Medicaid patients have equal access to a bed; however, this is not the situation in real life.

There is almost no protection through the federal laws and regulations for this situation. It would, therefore, appear that the State will have to take some action to protect this vulnerable group of citizens. The Finance Commission could take some administrative action that would probably help give some relief; however, it is my opinion that it will take State legislation to protect these citizens. I have drafted some language that will go a long way to reduce Medicaid discrimination. Rather than read the draft, let me summarize some of the provisions. The home cannot request or prohibit a person from applying for Medicaid, or to deny a Medicaid eligible person admission, it should prohibit the transfer of a patient because their status as a Medicaid recipient, or to charge any amounts in excess of the Medicaid rate and would assess monetary penalties for each violation. As I stated earlier, homes should be able to serve the private sector. However, the State has an obligation to protect the Medicaid population.

I would appreciate it if you would consider the items I have presented and give relief where possible. If there are questions, I will be happy to try to answer them.

Submitted by:

William V. Bradley
State Ombudsman

Medicaid Discrimination Draft

Because it is a matter of public importance to protect the citizens who need Medicaid services from discriminatory treatment in receiving long-term health care, nursing home care or other health care services, the General Assembly enacts the following:

Section (1) The purpose of this section is to prohibit discrimination against Medicaid recipients by nursing homes or other providers which have contracted with the department to provide skilled or intermediate care nursing services to Medicaid recipients.

It shall be unlawful for any nursing home which has a Medicaid contract with the department:

- (1) To deny admission or readmission of a person to a nursing home because of his or her status as a Medicaid recipient;
- (2) To require, as a condition of admission, assurance from the patient or any person that the patient is not eligible for or will not apply for Medicaid;
- (3) To transfer a patient to another nursing home solely because of his or her status as a Medicaid recipient;
- (4) To discharge a patient from a nursing home solely because of his or her status as a Medicaid recipient;
- (5) To charge any amounts in excess of the Medicaid rate established by the Health and Human Services Finance Commission.
- (6) Any nursing home which has a Medicaid contract with the Health and Human Services Finance Commission shall maintain one list of names of persons seeking admission to the facility, which is ordered by the date of request. The applicant shall be given their rank

in order at the time of application. This information shall be retained for one year from the month of admission. A list of requests for admission must be forwarded to the Health and Human Services Finance Commission each month.

Section (2) The Health and Human Services Finance Commission may assess monetary penalties not to exceed one thousand dollars for each violation. Each day a facility is found to be in violation shall be considered a new violation. All funds collected under this Section should be returned to the general fund.

Human Services Representative Harris observed that the Health and Commission would have to be given power to levy fines to carry out the provisions proposed by Mr. Bradley.



South Carolina Nurses' Association

1821 GADSDEN STREET
COLUMBIA, SOUTH CAROLINA 29201
TELEPHONE 252-4781

October 2, 1985

I am Daniel J. O'Neal, III, appearing on behalf of the South Carolina Nurses' Association Gerontological Special Interest Group.

One of the social functions which a professional association performs is the projection into the future of how its knowledge and skills may be applied in practice, in research and in teaching. The profession of nursing has a concern both for the quality of its service to the public and for the public view of nursing responsibilities. In keeping with those concerns for quality and the public view of the responsibility of nursing, the South Carolina Nurses' Association wishes to reaffirm the commitment of nursing to the exhuberant well being of older adults in South Carolina.

This audience present is well acquainted with the data about older adults in South Carolina - their numbers, their in-migration rates, their levels of functional ability, their use of services, the opportunities for employment and meaningful use of time, and so on. Some here present may remember as far back as 1958, when the American Nurses' Association was the first health profession to support health insurance for older Americans. Even though the method to address health insurance was too costly over time and has undergone significant change in the recent past, the South Carolina Nurses' Association hopes this audience will take heart—and will take heart in—this bit of history of nursing's recognition of the uniqueness of older adults in our society.

Constituent, American Nurses' Association

Page #2
Daniel J. O'Neal, III
October 2, 1985

Nursing continues to practice among diverse populations of older adults in all settings: home, work site, hospital, long term care institutions as well as other community-based settings. Problems of access to coordinated, comprehensive health care for older adults are addressed in part by access to the practice of nursing. The scope and detail of nursing's knowledge base has made great strides in the recent past in terms of identifying how variable older adults are one from another, in terms of having multiple disease and/or functional losses may affect a given older person, in terms of appreciating the atypical response of an older adult to disease and to treatment of disease, and in terms of the very wholesome response of older adults to learning new information and making change in their lifestyles.

Nurses possess an inventory of programs, skills, activities and one-on-one practices which are helpful in promoting health and preventing disease among older adults. Some of these skills and activities are being implemented in new and old models of practice for delivery of nursing to older adults. Some of these models require of nurses a larger measure of independence and interdependence with other health professionals than the public or, indeed, other health professionals have been used to in the past. The South Carolina Nurses' Association urges this audience to support these new models of delivering nursing knowledge and skills to older adults. Nurses are ready to help determine the effectiveness of these new approaches, to compare them with tried and true, and to assume accountability for the practice with older adults.

Page #3

Daniel J. O'Neal, III

October 2, 1985

The South Carolina Nurses' Association hopes that older adults will continue to have access to nursing's unique knowledge and skills since nurses can effectively and efficiently participate in the comprehensive assessment, planning, intervention and evaluation of care provided older adults. We stand ready to assist in the forming of coalitions of consumers and providers of care to make sure scarce resources are shared in collaborative, cost-effective ways among those who have needs, regardless of the age of the consumer.

The South Carolina Nurses' Association joins with other members of this audience in committing our energies to the goal of well being for older adults in South Carolina.

PRESENTATION TO JOINT LEGISLATIVE STUDY COMMITTEE ON AGING

WEDNESDAY, OCTOBER 2, 1985 - 2:10 PM

BLATT BUILDING - ROOM 101/109 - COLUMBIA, S.C.

I am pleased to speak about the Medical University of South Carolina's initiative in geriatrics and gerontology.

Many of you are aware that the late William L. McKnight, retired Board Chairman of Minnesota Mining and Manufacturing Company, honored Dr. Edwin Boyle, Jr. with an endowment of one million dollars to support Dr. Boyle's work on the many aspects of aging. When Dr. Boyle died in a tragic car accident, the McKnight-Boyle Chair of Gerontology was created to honor Mr. McKnight and Dr. Boyle. This philanthropy has provided the focus for gerontology and geriatric programmatic linkages within the College of Medicine and the other Colleges of the University.

As a result, there is now an active university gerontology committee with representatives from each college; the committee has considered the clinical, educational, research, administrative and community responsibilities of the University.

We have established a new Division of Geriatric Medicine within the Department of Internal Medicine and we are now in the process of developing a multiphasic geriatric evaluation clinic.

Dr. Benjamin Goodman is the principal investigator of a \$350,000 grant for the Department of Family Medicine to increase the opportunity for learning more

about health care for the elderly.

The College of Pharmacy is now emphasizing geriatric education in the curriculum. Their Curriculum Committee is studying a proposal which would make geriatric pharmacy required by all students. Pharmacy students are participating in programs involving senior citizen centers, congregate meals, home health care visits, and long term care facilities.

The College of Allied Health is developing a course in gerontology that would service the graduate and undergraduate programs.

The College of Nursing is placing more emphasis on gerontology and geriatrics in their training programs.

The Medical University actively participated in the formation of the South Carolina Gerontology Center.

Dr. William M. Simpson, Jr. has returned after a one year Hartford Geriatric Faculty Fellowship at Johns Hopkins. We are actively recruiting new faculty for our geriatric programs.

RESEARCH PROJECTS

Osteoporosis is a major cause of bone weakness which often leads to premature fractures in elderly patients. Dr. Norman Bell has received a \$600,000 grant to help identify the metabolic cause of this serious problem.

Dr. Betty Roof is investigating the treatment of post menopausal osteoporosis with estrogen and progestogen.

The Department of Basic and Clinical Immunology is investigating the effect of certain "memory restoring" drugs on immunocyte function in patients with Alzheimer's disease and the possibility of correction of immune dysfunction with these drugs.

Dr. Rosalee Crouch has a research grant to study the aging of the lens and cornea.

The Department of Dermatology is studying the aging of the skin resulting from excessive exposure to sun light.

Dr. Maria Virella is conducting research on atherosclerosis involving lipids and lipoproteins and how they affect the blood vessels.

The Department of Pharmacology has received over five million dollars in grant funds to study signals and receptors. This is the molecular investigation of the genetic control of hormones and receptors that regulate many processes in the human. These investigations will attempt to shed light on the adaptive processes involved in aging. This is on the cutting edge of research.

These are a few of the research projects directed toward aging at the Medical University.

We are actively planning a regional geriatrics center and a rehabilitation hospital with an Alzheimer's disease unit. We welcome input from groups or individuals in this planning process.

Careful planning is essential as we develop a successful program in gerontology and geriatrics. To improve the care of the elderly, the Medical University must have an excellent educational program for our undergraduate and graduate trainees. Excellent models in clinical care and research are required for success.

I am excited by the enthusiastic response of our faculty in this effort to improve the health status of the elderly.

Thank all of you for your attention.

Allen H. Johnson, M.D.

McKnight-Boyle Professor of Gerontology

Professor of Medicine

Representative Blackwell asked if there was any way as a state we could say to a student, "we will accept you and license you if you will accept Medicare as total payment for your patients." This is a constituent problem. He asked if there was anything we could do to encourage doctors to cooperate with their patients.

Dr. Johnson responded that at the Medical University most physicians accept the Medicare assignment. With physicians in private practice, it is a philosophic problem. He thinks that physicians' fees are too high (not charging too much, but costs are too high.)

Representative Blackwell asked if there was anything we as a state could do to more or less guarantee that Medicare and Medicaid supplement insurance would cover costs.

This matter was discussed and Dr. Johnson agreed that this was a difficult issue.

(transcribed testimony)

I came here hoping there would be some Senators so I could put the responsibility on them for passage of the "Living Will" bill. The bill did pass the House in good shape. I came to urge them to take responsibility for passage of the bill. This committee endorsed it and the House members worked for it. I hope they will not let another session go by and have it gone. Quite a few states have passed the bill. We are the only southern state who has not passed it. I was talking to a trust lawyer in Hilton Head and he stated that 50% of the people wanted him to draw up a "Living Will". They come from different states. He can do it but it does not mean very much.

Rep. Harris said it was through Rep. Keyserling's efforts that they were able to pass it through the House. He hopes others will implore the Senate to pass the bill. If it does not pass it will have to be reintroduced in totality and the process will have to start over again.

Rep. Keyserling urged them not to vote for any amendments that would make the bill worthless. Two amendments have been proposed so far.

Marguerite R. Howie
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SC State College
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Joint Legislative Study Committee on Aging
Public Hearing Chamber
Blatt Office Building
Columbia, South Carolina

POSITION STATEMENT
2:20-2:30 p.m.

Agency Utilization and Client Satisfaction
in Reference to South Carolina

Marguerite Rogers Howie
Professor of Sociology and
Principal Investigator, 1890 Research
South Carolina State College
Orangeburg, South Carolina

October 2, 1985

Agency Utilization and Client Satisfaction
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The concerns affecting the elderly are extrapolated from a ten state regional survey, namely Alabama, Arkansas, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, Tennessee and Virginia. The project was funded by the United States Department of Agriculture.

Although nine agencies were included in this study (Employment Security, Food Stamps, Farmers Home Administration, Social Security, Commission on Aging, Health Services, Mental Health, Veterans Administration and Vocational Rehabilitation) my statement treats the Commission on Aging, Food Stamps, and Social Security. These three are used by a greater percentage of senior citizens than the remaining six.

In regard to utilization, the populace is inclined to think that Food Stamps and Employment Security are the agencies most understaffed, South Carolina, along with Arkansas and North Carolina have the greatest number of clients to serve for each full-time employee. And, the Commission on Aging had the largest case load per staff worker than any of the agencies. Of these clients, 70 percent are in poverty and South Carolina ranked fourth highest in the service of persons 65 or older.

To treat client satisfaction as a concern, a digest of availability and accessibility will be elucidated. The agency

directors ranked their five pressing needs to be (1) inadequate staff, (2) insufficient capital or money, (3) lack of transportation, (4) need for better equipment, and (5) facilities.

The agency directors' questionnaire revealed that the means of publicizing their agencies were the newspaper, radio and TV. However, the household respondent reported that they secured knowledge about agencies "from a relative or friend" or "referral by a social service agency." This means that if one is not using an agency which may refer him/her to the Commission on Aging, the probability is high that he has need for a friend or relative to inform him of the services. The outreach programs used by the agencies are ineffective in contacting probable clients.

In regard to accessibility, in South Carolina only one-fourth of all agencies provide transportation while in the other seven (7) states one-third or more of the agencies provide this service. Regionally, one of three persons utilizes Food Stamps and of those in poverty, approximately one half use the agency services. South Carolina is the third highest state whose users rate Food Stamps services as "fair to poor."

Of the recommendations made in Dimensions of Poverty in the Rural South based on the findings of this study, the six that specifically refer to the dilemmas of the senior citizen are:

1. Financial support: Where federal and state grants are available, (a) elasticity in the provisions for recipients who are elderly, (b) deferred payments for clients affected by economic slumps and natural disasters, (c) escalation of benefits commensurate with the cost of living index, and (d) retention of

eligibility for dependent or disabled persons if the household recipient fails to comply with any stipulated requirement(s) should be maintained.

2. Client review rights: Whereas persons utilizing agency services are, generally, those who can least afford delays in service delivery, policies involving red tape appeal tactics and waiting periods for beginning of services should be re-evaluated and re-structured so as not to discriminate against the total household.
3. Benefits involving fuel: Whereas energy, per se, is the need, benefits involving fuel should be inclusive of any type commodity within the energy producing category.
4. Communication and outreach media: Whereas the recipients or probable recipients of an agency service represent the target population, communication and outreach programs should be enhanced via the channels most effective for the populace.
5. Transportation of clients: Whereas transportation poses a hardship and burdensome expense to limited resource clientele, agencies may well do feasibility studies to ascertain the functionality of including transportation for the relevant sector of the clientele.
6. Client satisfaction surveys: Whereas most recipients of agency services are in subordinate positions to register complaints, client satisfaction surveys should be encouraged as a part of the agency evaluation process.

REFERENCES

- Howie, Marguerite R.
1984 "1890 Regional Research (RR-I) Brochure No. 1: Profile of Rural Population in 10 Southern States: Utilization of Agency Services," Orangeburg, SC: 1890 Research South Carolina State College. March.
- Howie, Marguerite R. and Robert L. Phillips, Jr., South Carolina State College
1985 "Recommendations Pertaining to Policies Affecting Availability, Accessibility, and Utilization of Agencies" in J. S. Dhillon and Marguerite R. Howie's (editors) Dimensions of Poverty in the Rural South. Tallahassee, FL: Florida A. and M. University. November. "In Press"
- Howie, Marguerite R., South Carolina State College; Lina Godfrey, University of Arkansas at Pine Bluff; Alton Thompson, North Carolina A. and T. State University; and Robert L. Phillips, South Carolina State College
1985 "Availability, Accessibility and Utilization of Agency Services" in J. S. Dhillon and Marguerite R. Howie's (editors) Dimensions of Poverty in the Rural South. Tallahassee, FL: Florida A. and M. University. November. "In Press"
- Wheelock, Gerald, et al.
1983 Isolation of Factors Related to Levels and Patterns of Living in Low-Income Areas of the Rural South: A Basebook. Normal, Alabama: Alabama A. and M. University, 1890 Land-Grant Regional Publication No. 1. August.

Dr. Parrish asked if Ms. Howie would make the findings from their study available.

Ms. Howie stated that the Committee will be receiving copies of the publication due to come out in November.

Barbara L. Ginn - private citizen
West Columbia, S. C.

I am here today as a private citizen who has a special love for the elderly, and a special concern for the elderly in nursing homes.

I have been visiting in nursing homes over the years - for the Church, when my mother-in-law and then my mother were in homes for periods of time, and because I feel a real desire to be there.

The elderly have many problems, and we are all familiar with these problems. Usually, in nursing homes, these people's problems are compounded. These older citizens have been separated from their families and friends, they are placed in unfamiliar surroundings - with people they have never seen before. Most are never visited by anyone. They rarely see a doctor, especially their own doctor. They are probably chronically ill, and some are bed-ridden. Some are not able to comprehend their surroundings. The food is usually not good. Most importantly, there are not a sufficient number of workers to meet the basic needs of the patients - needs like going to the bathroom, or using the bedpan, being put to bed for naps, or being fed their meals.

These people are being warehoused like merchandise.

Although I know some very good workers in nursing homes, the employees are mostly low paid and are only working at a job. And then, much outright abuse goes on, physical and mental abuse.

Barbara L. Ginn

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A change in the method of caring for the elderly must be brought about. Millions of dollars of the elderly's pensions or Social Security, supplemented by Medicaid and Medicare, are being paid for care that is not received. Surely we can find better ways to spend this money so that these people will receive adequate care.

An in-home, hospice type program could take care of many of these elderly patients who only need someone to administer medicine or check on them. This could be done in conjunction with "meals on wheels". In many cases these people could remain in their own home or in the home of a family member who must work at an outside job. Day care centers for older citizens who cannot be left alone is an excellent alternative to many persons being housed in nursing homes. Even having an attendant/aide stay in a home all day with a sick person would make better use of the money being spent presently. The cost of the building would not be a factor as well as the costs of supplying everything for the patient, from utilities to bed linens.

What I am saying to you today is that definite changes need to be made in caring for our elderly citizens. The nursing home business in this country, with few exceptions, is being operated at the expense of Elderly America.

Euthanasia is not the answer to the problem of taking care of these elderly citizens. God alone, who is all merciful, is the Giver of Life.

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He also has given us all-powerful love. This love should motivate us in taking care of these problems with life - while we leave the taking of life to the Author of Life.

Our elderly citizens are important to our society. We must not let them be second class citizens. They represent our heritage, our roots, and they are of much value.

What will be the quality of care the elderly receive in this country, in this state, in the years to come?

Where are we headed?

Where will many of us here in this room be in 20, 30, 40 or more years?

If nothing is done to change the present system into something better, many of us here in this room today will experience first-hand the hopelessness of our present typical nursing home situation, or worse. We need to be concerned. We need to be positive. We need to realize that we can devise a better system, and we need to do it.

Linda C. Hall
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JOINT LEGISLATIVE STUDY COMMITTEE
ON AGING

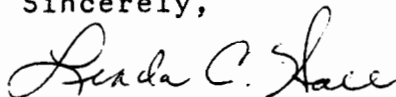
PUBLIC HEARING
OCTOBER 2, 1985

There are a number of issues that are general concerns that I would like to share with you today.

1. The growing elderly population of our state is already creating new needs and requiring adjustments to our services and programs to serve a more diverse elderly population.
2. Premature discharges from hospitals are returning patients to their homes in more frail circumstances and with more complex needs putting a real strain on existing in-home services.
3. Respite Care needs continue to grow due to additional care required of family members. Families are as much victims of Alzheimer's Disease as the patient.
4. There continues to be a need for nursing home beds. Patients with the ability to pay privately have long waiting periods and medicaid patients can only get beds in a crisis situation. Our other state institutions are absorbing some of the backlog even though they are poorly equipped and staffed to do so.
5. The commitment process still allows a person to be subjected to commitment on the word of a family member or neighbor and a Probate Judge who has no legal, medical or social services background. This is a great injustice to our general population and an even greater one to our elderly who have special needs and are easily intimidated by law enforcement, doctors, and judges.
6. Our elderly have not been given the right to refuse medical treatment that can cause pain and loss of dignity. Society has no right to end in humiliation and loss of dignity lives that have been productive and filled with pride. The decision of how one lives one's life is a personal choice and the decision to end a hopeless life with dignity should be a personal choice.

I thank you for the opportunity to share my concerns with you.

Sincerely,



Linda C. Hall
Coordinator, Lexington County
Aging Program

Representative Blackwell asked if Ms. Hall was going to comment on the Planning and Servicing Districts Configuration.

Ms. Hall replied that she would leave that discussion to others.

Presentation Before The Joint Legislative Committee On Aging

By: Fletcher Spigner, Executive Director

Council on Aging of the Midlands

October 2, 1985

I do want to express my sincere appreciation for this opportunity to make a few comments about what I feel is the most significant concern facing older people in our State today.

My name is Fletcher Spigner, and I am the Executive Director of the Council on Aging of the Midlands, located here in Columbia. We are the largest and one of the best Councils on Aging in South Carolina. I feel that we have been leaders in providing many services to older people at the local level through many successful and creative ventures. We have done this with the tremendous support of our Area Agency on Aging, the Central Midlands Regional Planning Council, and through the existing state agency network of services to older people.

I believe that the number one issue facing the aging program in South Carolina is what I call "effort, energy, and enthusiasm dilution." In this state we have no fewer than six to eight major state agencies expending tremendous amounts of energy on behalf of older people. In a quantity oriented society, this looks pretty good on paper, but it is my contention that this fragmented effort by our state hurts the aging program very badly and just about has to be the most inefficient way of serving the most rapidly growing segment of our population. Therefore, I am recommending your serious consideration of a single state agency to administer services to our older people.

We would correct a number of problems if a single state agency were designated. There would no longer be a lack of coordinated leadership at the state level, where now only tunnelvision views of problems affecting older people exist. Each agency is concerned about its programs and services, and

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because of the fragmentation of effort, energy, and enthusiasm across the state, these agencies have become very frustrated in trying to meaningfully coordinate their efforts. Our collective effort, particularly as the aging program grows and becomes an even more important public policy issue, is being sabotaged by the very system set up to ensure an efficient and effective program.

Another problem which could be taken care of by the establishment of a single state agency is your own relative lack of policy control, even though you are elected by the people to establish and coordinate, from a policy standpoint, those services benefiting our citizens. The Joint Legislative Committee on Aging has done a yeoman's job in coordinating policy, but I would suspect that the job would be a whole lot easier if you all were dealing with one good, strong state agency commission, from which you could receive exact and effective leadership and over which you could exert legitimate control in the name of the people of South Carolina.

Finally, the Governor's Office suffers as well because he, as Chief Administrative Officer of this State, has to deal with so many people and so many programs that his administrative power, appropriately vested, is nevertheless diluted. The Governor, in concert with strong leadership at the single state agency level, could effectively and efficiently administer the laws and policies of our state.

If there is one action that would unify our collective efforts, it would be to establish a single state agency. More power to the legislature, more power to our state's chief administrative officer, and most importantly, more power to the older people of South Carolina.

Because issues affecting older people are of rapidly growing concern, the time is ripe to usher in this new era with a strong, effective mechanism that deals directly and exclusively with the concerns of older people. Let us not be tempted to dilute our efforts any further by continuing to spread aging programs out among numerous state agencies. Let us not yield to a segregation of aging programs by function. For aging professionals are best suited to administer health, social, and community-based programs for older people because people problems affect older people more acutely and more uniquely than any other segment of our adult population.

Therefore, let us gather the experts in our field under one roof to work with you and the Governor to achieve a truly outstanding aging program in South Carolina.

Thank you very much.

Fletcher Spigner

Representative Blackwell asked Mr. Spigner to furnish the Committee with a list of those eight or more agencies so they can consider whether they should pull them all together.

Mr. Spigner agreed to supply the list and Dr. Parrish urged the Committee to take this matter under serious concern within the Committee meeting.

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My name is Susan Wrigley. I am President of the South Carolina Adult Day Care Association and Executive Director of an adult day care facility here in Columbia. More importantly today, at one time I was a granddaughter whose 83 year old grandmother needed community supports to remain in her home. The support was not available and in time she entered an adequate nursing home near her small town in the upstate. Having been a mill worker for most of her life, her resources were limited so Medicaid was needed to supplement the cost of the nursing home care. But there were frustrating strings attached to that help. I was billed for more than one hundred dollars in so called "extra" cost each month and she could spend no more than one night at a time at my home here in Columbia. This meant a 140 mile round trip two days in a row for me and a tiring automobile trip two days in a row for her.

This marked just the beginning of the frustrations and disappointments associated with her care that ended with her death two years ago. Her treatment as a second class Medicare patient by two hospitals could be the subject of another speech.

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Of course, institutions, agencies and third party payers must have guidelines and regulations. For good or bad who pays the bill and how much they pay to a great extent determines what type of care is available. Older adults have a right to care in the least restrictive setting possible, yet it is estimated that one half of the residents in nursing homes do not need to be there. My grandmother went from living alone in her own home one day to being a dependent patient the next day though her health and functional level had not change. Community supports such as adult day care can delay the arrival of the day when someone needs intermediate care in a nursing home. A positive step in that direction was made for South Carolina when an additional 250,000 dollars of state money was allocated to assist the South Carolina Commission on Aging with the provision of community based services for older adults.

It is well recognized that the demand for services will increase. Let us not save our best effort for 15 to 25 years from now. Resources can be developed now while the potential client pool is relatively small. It is already too late for my grandmother. Tomorrow will be too late for someone else's grandmother.

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The South Carolina Adult Day Care Association is concerned that there are wide variations in the application of fire regulations to the adult day care setting in South Carolina. Depending upon which fire authority you ask, you may be told that children's day care regulations or residential care facilities' regulations or educational use regulations apply to adult day care. Seemingly capricious interpretations of fire regulations can play havoc with a facility's budget when it is suddenly required that an expensive fire alarm system be installed or all the paneling either be removed or be treated with fire resistant material.

Collectively, the members of the Association have many years of experience in adult day care and would welcome the opportunity to assist with determining appropriate fire regulations for adult day care facilities.

As a member of the Geriatric Specialists Advisory Council, I wish to address some of the grave issues that elderly Americans must face on a daily basis.

For the past 3 years, I have worked as the Co-ordinator of Elderly Services at the Orangeburg Area Mental Health Center. During these years I have seen the distress of our senior population and have been shocked and appalled as I watched in dismay the struggle they are forced to endure just to survive.

As the elderly are buffeted by life's vicissitudes, I have seen patient's have to make the choice between buying food or buying medicine because Medicaid will only pay for three prescriptions. Others who have lost family members face loneliness, isolation and neglect as often the attitude is, "Why worry about the elderly, they have lived their lives and are just waiting to die." Senior Americans are forced to carry the horrendous burden of Agism and face the gross insensitivity of a youth oriented society.

On assuming my position as the Co-ordinator of Elderly Services, I took a needs assessment of my clientele and found that the two overwhelming problems they faced were health problems and financial problems.

These problems in turned caused severe stress and led to emotional problems such as depression and anxiety which compounded their physical complaints.

My Counseling and Advocacy seemed a mere drop in the bucket. While the State considers Children's services as a priority, funding for the elderly remains inadequate. As population of elderly citizens increases, the problems they and society as a whole will be exacerbated if something is not done.

What is the solution? Dr. Hilda Ross, who was the Director of Services for the Aging for the Department of Mental Health pointed to a solution. She had implemented a program in Miami, Florida called the "Neighborhood Family" which was a living skills program for the elderly.

The "Neighborhood Family" is a facility located away from the center that is operated by the patients themselves. It is a place that provides patients with an accepting, warm atmosphere where each person not only learns and implements new skills but can enjoy fellowship, feel useful, and most importantly feel wanted. In short the program provides a surrogate family for those elderly who are alone. For those elderly that are still living with a biological family, it provides an outlet for the patient and respite for the caretakers of the biological family, thereby preventing burn out from stress.

After 9 months of diligent preparation and coordination with other social agencies, our center started the first living skills program in Orangeburg, South Carolina.

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The response has been excellent. The "Neighborhood Family" members are very faithful in their attendance. The program has grown from four hours a week to eight hours in only six months and is still growing.

The "Neighborhood Family" involves many other agencies in the Community such as the Health Department, the Council on Aging, Long Term Community Care, the Department of Social Services, The Tri-County Commission on Alcohol and Drugs and several residential care facilities just to name a few. The support and involvement from these agencies has been tremendous. The cooperation afforded me was so vital to the "Neighborhood Family" that I would not have been able to implement the program without it.

The "Neighborhood Family" members have thrived. Not one has returned to Crafts-Farrow. Patients who were thought to be "over the hill" are learning new skills. Depressed and anxious patients have improved dramatically. One non-verbal, withdrawn patient has become loquacious, and his social skills continue to improve. Another patient insisted on attending each meeting even though she had a broken ankle and was in pain. Several patients who have been in the hospital for years are now interacting and socializing better than they have for years.

The "Neighborhood Family" also serves as a mode of prevention because of the fine medical screening done by our nurse and psychiatrist. Because of the emphasis on medical education, evaluation and screening, problems are discovered ~~and~~ early. Because of our efficient nursing staff and excellent rapport with the medical community, we discovered that one patient's depression was really a result of a thyroid condition. That patient has returned to work. Early diagnosis and treatment of another patient's diabetes allows him to control his condition with diet rather than chemotherapy.

Since about 40% of all psychological problems are caused by medical conditions, the Neighborhood Family prevents patients from being placed in Crafts-Farrow. A significant benefit for the patient as he can remain in the community and also less costly for the state.

The "Neighborhood Family" can be viewed as a pilot project. If each Mental Health Center had one, admissions to the Crafts-Farrow would decrease. Patient's healthier, happier and the State would save money as the "Neighborhood Family" is a project that can give quality care to a large number of patients with a minimal of staff.

The one question that I am most often asked is, "How is the Neighborhood Family different from services provided by the Council on Aging?" The differences are significant.

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1. The "Neighborhood Family" caters to a clinical population.
2. Our program provides health education and screening. A nurse and psychiatrist are a vital part of the operation. The "Neighborhood Family" members are monitored frequently. If referrals to the medical community are warranted the nurse immediately refers.
3. The patients become family members.
4. The "members" are the planners and decision makers. This in itself is better therapy than medicine as it places control in the hands of the "Neighborhood Family" members.
5. Emphasis is on active participation and independence. Neighborhood Family members do for themselves as much as possible.
6. The "Neighborhood Family" accepts patient's who function on different levels and improves their level of functioning.

I should like to see a "Neighborhood Family" in every community in South Carolina. Surely funding is needed by each center but what could be saved by the preventive measures afforded by the program far outweighs the initial costs. The Governors resource panel and implementation committee have recognized the "Neighborhood Family" as an important priority.

CAROLYN RATHLE, M.Ed.
Coordinator of Elderly Services

CR:bw

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Legislative Study Committee on Aging

H. K. Ross

Oct 2, 1981

ISSUE PAPER

AUSTERITY AND THE AGING

This year, a statement on austerity and its impact on services is appropriate. It is a subject addressed more and more in the literature and the recurring theme in the journals and texts is the right of citizens to services and the "prescribed austerity". Public policy decision makers search for a balance between service rights and the scarce dollars. Recent publications write about "perceived austerity" and the "images of problems of austerity" indicating that what we have come to accept as austerity "may not be entirely based on facts", and that our thoughts are being shaped by the politics and current ideologies. This theme is developed in Fiscal Austerity and Aging, an important book by gerontologists and scholars Carroll Estes, Robt. J. Newcomer and Associates (1983). It is based on seven years of research coming out of the Aging Health Policy Center and the Department of Social and Behavioral Sciences, School of Nursing, University of California. They point out that the continuing "idea of austerity" serves well to rationalize the currently growing economic difficulties and is effectively divisive (1) in pitting the needs of the young against the old, (2) in igniting agency aggressiveness in scrambling for the now well accepted scarce dollar and, (3) in masking massive Federal fiscal changes and the direction of expenditures away from human services. With austerity applied to human services primarily, the impact on the total client populations and the c.m.i. elderly in particular becomes apparent.

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Nationally, the current distraction is to point the finger for the fiscal crises on the aging society as seen by attacks on Social Security, Medicaid, Medicare, wrongly equating deficits with an expanding aging population.

THE STATE. In S.C. public policies for resolving needs of aging individuals has always reflected economic swings and the political interests surrounding them, however, today the SCDMH faces a new phenomena, a rapidly growing aging population of whom 15 to 25% will require some kind of mental health services.

Unquestionably, the Department maintains the citizens right to mental health services. Among an array of services, a few are psychiatric care, counseling and case management which assists a client to the services provided by other agencies. Mental health problems can be caused by the biological but also by the interplay of deprivation, deteriorating socialization, and a distressful environment over which the SCDMH does not have control. Therefore, decisions based on austerity affecting other agency's services, and not even directed to unwell elderly clients, do in time impact on the aged, i.e. fewer DSS staff to provide services, reduced budgets decrease services, lean budgets to build low-income housing, limited transportation to provide access to services, Mental health problems can result from the complications of these external forces. For the elderly, who may be experiencing problems, entering the ranks of the unserved or the under-served becomes a terrible weapon of human destruction.

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Therefore, the SCDMH is concerned when agencies, other than itself, experience lean budgets. There is ample documentation beginning in the 1800s to show increased admissions into psychiatric hospitals and higher suicide rates during times of austerity. (J. Brenner. Mental Illness and the Economy). Since the SCDMH has an open door policy, additional clients can be anticipated not only due to austerity measures but to the aging demographics as well.

For Department of Mental Health clients 55 years and over, in the last six months compared to the same period last year, all admissions into our hospitals show a 5% decline. This is good, but still not sufficient to achieve decreased hospital population goals, and the Community Mental Health Centers show a 10% increase.

How shall the Department regard the multi-faceted external conditions which continue to overwhelm its facilities and personnel? A third of our hospital patients do not require psychiatric care. So, where does the responsibility lay for assuring a sound financial base, comprehensive medical care, rectifying a distressful and deprived environment, meeting housing needs, assuring reasonable resocialization and productivity, most factors beyond the psychiatric pale but which are major contributors to it?

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STATE EFFORTS. Given the current political view that the problems of the disadvantaged are not to be financially supported from Washington, South Carolina seeks solutions: 1. from its legislative, corporations, churches, and through individual effort, 2. from the Governor's panels ~~to~~ reviewing unemployment and ^{indigent medical} Medicare care. For the DMH, (1) there are fewer mental health workers carrying larger caseloads, (2) staff is asked to be more creative in ways which do not require dollars, (3) to improve utilization of another agency's services, (4) to increase use of volunteers. The SCDMH actions are prodigious: (1) It has moved through a major restructuring which allows for increased support for Community Support Program, (2) as improved staff/patient ratio occur in hospitals, intensive therapeutic programs for targeted populations are initiated, (3) it is exploring methods of making the Community ^{mental} Health Center the point of entry into the psychiatric hospitals.

So, austerity brings good practices but it also has damaging effects. We are pitting the needs of one group of clients against another and important fiscal decisions tend to be based on aggressive staff behavior and on staff values rather than on specific data-based information.

The critical question is "Does South Carolina have the tax structure to support the service needs of its people even with the current intensive effort to meet the challenge? It seems unlikely.

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The research study I mentioned states, "continued or expanded federal fiscal involvement in the health and human services is essential for States to meet the rapidly growing needs of their populations". Along with most of the State of this Union, South Carolina cannot go it alone without Federal assistance of sizeable proportions.

As pressures mount, what human indicators will set off our alarm system before we begin to question the current Federal posture? We need to ask, "for whom is austerity a challenge - the client or the agency? The SCDMH is already working at its limits in facing the challenge, as are all of the state agencies, but what about the elderly clients who are the last to be considered even in the best of times? What indicators shall we use to alert us that our excellent efforts are insufficient? Which bold questions do we ask before we collectively respond to the growing disparities and dangerous gaps? Which indicators shall we use for the c.m.i. elderly: the number of unserved and underserved, the higher suicide rate, the increased numbers of admissions into psychiatric hospitals and community mental health centers, the flight of overburdened, underpaid staff, the increased number of elderly abuse cases? At which point do we agree that the elderly client has become the victim? If we believe that the elderly people are worth investing in, then we need to know when our efforts have been overwhelmed.

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We need to be forthright in acknowledging that the expansion of state financial responsibility, if that is at all possible, will not solve the problems of financing the mental, physical, environmental, health and the social services needs of our unwell elderly population.

State funding will be insufficient, but some of the slack can be taken up by giving the elderly a greater voice in services concerning them. Three suggestions are:

1. That health planning bodies and institution boards include older consumers as planners, may I emphasize planners and managers, in services affecting their age group.

2. Prevention needs to be given a key role. Elderly people respond remarkably well, they get better with early intervention and rehabilitative services. In South Carolina we have the Neighborhood Family, a prevention model for the elderly where early intervention services are available. The client evaluates his needs, determines what is important to him, in fact becomes the responsible agent for much of what occurs in services regarding his welfare. When the clients become the responsible planners and managers, the efficient and effective use of services is almost guaranteed.

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3. We have numbers of senior centers which need very little more to become comprehensive multi-purpose senior centers. I propose that we bring mental health services into senior centers and that the SCDMH, COA and others jointly explore the methods of also bringing their services into these Centers. Secondly, that the Centers operations be based on the Neighborhood Family concepts, where the elderly people select which services they need to bring into their Center and when they want them. This kind of high level linear involvement of the elderly people with the providers can address many of the mental health, social and health problems within the therapeutic milieu of resocialization and productivity. The city of Baltimore has 12 great comprehensive Centers, one in each section of town. A visit to one is a memorable experience. If austerity cut-backs do not further erode agency services, then with modest agency realignment for directing services into the Center, South Carolina could have one, too.

In summary:

1. that there be several vigorous public debates which address austerity and aging and where hard issues and bold questions dare to be raised.
2. that the SCDMH and COA review the procedures for developing a pilot comprehensive senior center where mental health services as well as other agency services are centralized.
3. that a prevention model, primarily the Neighborhood Family, be developed where elderly at risk, and ^{the} families caring for unwell relatives can participate as co-planners with the professionals in developing services concerning them. Thank you.

TESTIMONY PRESENTED BEFORE
THE JOINT LEGISLATIVE COMMITTEE ON AGING
OCTOBER 2, 1985

by Ernest Furchtgott, Ph.D.,
Director, South Carolina Gerontology Center

Thank you very much for again providing me with the opportunity to appear before your committee.

Since I last appeared before you the South Carolina Gerontology Center has been established. Despite some concern voiced by some members of this Committee as well as by many individuals in the gerontological community in the State, Clemson, The Medical University of South Carolina, South Carolina State College and the University of South Carolina did agree to develop a consortium for the study of aging. Winthrop College may join the consortium by January 1, 1986. This joint effort was applauded by the "Greenville News" and in Columbia "The State." The latter in an editorial no less, on September 11, 1985 entitled "Pooling Our Resources" called it "a sensible consortium" which in the long run should relay helpful results to those who provide services to the aging.

The major objectives of the Center are to promote research and to assist in knowledge transfer from research findings to applications. Combining expertise scattered in four separate State institutions is a more economical approach than having gerontologists knowledgeable in diverse areas employed by a single institution. We must remember that

gerontology encompasses many areas including architecture, biology, economics, law, nursing, pharmacy, medicine, physical education, psychology, recreation, social work, to name just a few. The Directory published by the S.C. Gerontology Center indicates that our State institutions which are members of the Center do possess expertise in a very large number of areas. No single school in South Carolina can afford to employ such diverse talent. Similarly, no state agency could justify having a very large number of researchers on their staff who would provide the needed expertise. Gerontology is a multifaceted discipline. While we do have major state agencies in South Carolina whose functions are in assisting with service delivery, such as the South Carolina Commission on Aging, the Departments of Social Services, Health & Environmental Protection, Mental Health, etc., none of these agencies, however, has many, if any resources to conduct research immediately applicable to problems in South Carolina. Yet, for the most efficient delivery of services data and information are needed based on local conditions. For example, Dr. Hilda Ross, formerly in charge of the Office for Services for the Aging in the Department of Mental Health told me that for planning purposes the Department had to use national norms on the prevalence of various mental health problems among the aged in the State. Given local conditions, such national data may have limited validity. Also, she needed information on the most effective techniques applicable to the treatment of several mental health problems with populations with limited education. Parenthetically, Dr. Ross retired several months ago and the Department of Mental Health has not filled yet the

position of coordinator for Services for the Aging. Another example of needed information was given to me by the Department of Social Services. They are interested in techniques for finding the elderly who are abused as well as some data on the incidence of such abuse. A third example of needed information comes from Mr. Winston Thomas in the Governor's Health and Human Services Division. Different state agencies use widely discrepant demographic data on older individuals in South Carolina. These discrepancies may have significant implications for the delivery of services. These are just a few examples of immediately needed research.

A Citizen's Advisory Board representing State agencies and citizens groups concerned with the well-being of our elderly suggests to the Gerontology Center activities which it ought to undertake. Ms. Keller Barron represents your Committee. During the initial meeting of the Advisory Board several excellent suggestions were, indeed, presented to the Gerontology Center.

The South Carolina Gerontology Center was established in February 1985. None of the consortium members had or has a specific budgetary line for the support of the Center. For 1985/86 each of the four schools is contributing \$6,550 toward support of the Center for a total budget of \$26,200. The total represents less than one-hundredth of one percent of the state's funding for higher education. Most states have at least one state supported gerontology center. Several states in the region have more than one such center, e.g. Alabama has two, Florida has four, Georgia has two, Virginia has three. We

recently conducted a survey and found that last year the median state support of gerontology centers was over \$70,000 per year.

The need for research on aging is well known. A recent (September 18, 1985) article in the Chronicle of Higher Education which announced a new program by the John D. & Catherine T. McArthur Foundation on "successful aging" pointed out that we need information on general measures of a person's psycho-social and physical status to determine a person's capacity to respond successfully to physical, psychological, or social stresses. However, the study of aging currently lacks a strong academic base. Aging does not have a high priority in most institutions of higher education.

Let me indicate briefly some of the activities of the S.C. Gerontology Center during the first half-year of its operation. 1) Published a Directory of Research Personnel in Gerontology (a copy of this Directory was mailed to all members of your Committee); 2) facilitated the preparation of AoA grant application submitted jointly by S.C. State College and USC; 3) assisted the Director of the Joint Legislative Committee on Aging, the DSS Director of Adult Services, and the DMH coordinator of Services for Aging with literature searches; 4) answered inquiries from citizens and local agencies in the State; 5) published a newsletter reporting on gerontological research in South Carolina and on research opportunities; 6) the Director spoke to several senior citizens groups on gerontological topics; and 7) conducted surveys of programs in gerontological education and financial support of centers.

Support from your Committee was very helpful in the establishment of the Center. Now that we have established the feasibility of having a research center jointly operated by all doctorate granting institutions in the State its viability depends on the financial support which it receives. Your Committee is the most knowledgeable and interested legislative group dealing with the problems of our older citizens. Much research is needed on the local level, as I have indicated previously, to optimally use our limited resources. Thus, a very small investment in the types of activities which the Center can provide will more than pay for itself even in the short run. I am, therefore, requesting that your Committee propose adding an appropriation of \$70,500 for the S.C. Gerontology Center for the 1986-87 year. I have prepared a more detailed budget which I am appending to this testimony.

Let me thank you again for the opportunity to testify.

Budget for S. C. Gerontology Center
1986-87

Director 1/2 time salary & fringe benefits	\$36,000
Administrative Assistant - salary & fringe	21,500
Office Equipment	1,000
Office Supplies	2,000
Communications (telephone, postage)	2,000
Printing	500
Travel	1,500
Graduate Assistant to collect data	<u>6,000</u>
	<u>\$70,500</u>

The State

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6-A Columbia, South Carolina, Wednesday, September 11, 1985

Pooling our resources

ADVANCEMENTS in medicine are adding years to our longevity, and as a result the problems of aging are drawing more and more attention.

There are numerous agencies at the state and local levels in South Carolina which provide services to our elderly citizens. But there hasn't been any organization specifically devoted to researching the problems of the aging — until recently.

A South Carolina Gerontology Center has been established to promote and assist in gerontological research and development. Fortunately, it involves four state institutions which have graduate degree programs and support research: Clemson University, the Medical University of South Caro-

lina, S.C. State, and the University of South Carolina.

They have the faculty and the staff with expertise covering a wide range of disciplines involved in gerontology — biology, medicine, nutrition, nursing, public health, psychology, demography, sociology, social work, economics, and law. By pooling these resources, the research efforts can be more sharply focused, better supported, and involve interdisciplinary approaches which no single institution presently is capable of doing well.

This is a sensible consortium, and in the long run should expedite research, consequently relaying the helpful results to those who provide services to the aging.

Representative Harris asked if this \$70,000 would be in addition to the funding of \$24,000 from the university.

Dr. Furchtgott replied no. They do not want to give anything. He is the director but is not paid for his services.

Thomas E. Brown, Jr.
1801 Main St.
P.O. Box 8206
Columbia, SC 29202

PRESENTATION TO THE STUDY COMMITTEE ON AGING

October 2, 1985

Thomas E. Brown, Jr., Bureau Chief
Bureau of Long Term Care

S.C. State Health and Human Services Finance Commission

Representative Harris and members of the Study Committee on Aging, thank you for the opportunity of addressing the Study Committee at this Public Hearing. I would like to report on the progress of the Community Long Term Care Program and to address other issues which relate to the provision of long term care services in South Carolina.

The Community Long Term Care Program received Federal approval for Medicaid home and community based waivers in December 1984 and May 1985. These Federal approvals along with the State funding which had been appropriated in FY 1984-85 budget allowed the State's Medicaid program to offer a number of new home and community based services. These services include personal care, medical day care, home delivered meals, respite care, and home delivered therapies as well as expanded Medicaid eligibility to individuals who previously would have been eligible only if they were institutionalized. As of September over 85 new providers of home and community based services were enrolled in the Medicaid program and over 1,700 patients were receiving care through the CLTC system. This number of patients represents a increase of 48% between June 1st and August 31st. We anticipate that this rate of increase in the number of patients being served at home will continue throughout the remainder of the fiscal year and that approximately 5,000 individuals will be served annually through the CLTC program.

The State Health and Human Services Finance Commission budget request for FY 1986-87 includes funding to annualize the CLTC program budget. This increase is necessary because the initial year's funding included only partial funding for the program. I would like to request the Study Committee's continued support for the Program and its request to annualize the Program budget.

The second topic I would like to address is long term care insurance. In my testimony before the Study Committee last year I indicated the need to study the availability of this type insurance for the State's elderly population. Some progress has been made in this area since last year's hearing. Currently a number (5-10) of insurance policies are available in the State. These policies provide varying degrees of coverage for long term care services in either institutional or institutional and community based settings. A review of these policies is being undertaken by staff of the Finance Commission to evaluate their impact on the Medicaid long term care programs. Long term care insurance has the potential to reduce the number of Medicaid conversions or in some cases delay conversion among institutionalized patients. Currently, approximately 30% of the referrals to the CLTC program for Medicaid sponsored long term care benefits are individuals who are presently nursing home residents and care attempting to covert from private pay status to Medicaid. This rate is somewhat lower than the national experience which was estimated by the Congressional Budget Office in their 1977 study to be approximately 50%.

Other significant progress which is being made on the national level involves a joint effort by the American Association of Retired Persons (AARP) and the Prudential Insurance Company. In mid-October the AARP will begin marketing a long term care insurance policy which will be available to its membership in six states. This policy has a relatively comprehensive benefit package which provides for institutional and home based care. The policy will be available to individuals between the ages of 50 and 79 and will cost between \$14 to \$95 per month depending upon age. The maximum life time benefits under the policy are \$43,800 for institutional care and \$9,125 for home based care. Depending upon the success of this six state test, it is my understanding that the AARP will make this policy available to their membership in other states.

Although some progress is being made in the development and availability of long term care insurance, additional work by the State needs to be accomplished. In last year's testimony I recommended that the Study Committee on Aging take the lead with the State Health and Human Services Finance Commission, the Department of Insurance, Insurance Industry Representatives and Consumer Groups to draw up a plan designed to encourage the development of long term care insurance in the State. I continue to feel that this planning is necessary to address two major areas of concern: consumer protection and consumer education. A number of studies at the state and national level and our experience with the Community Long Term Care Program have shown that in general the elderly population does not understand the present long term care coverage offered under the Medicare program nor do they understand the requirements which they must meet to qualify for Medicaid. Specific information concerning these two programs as well as their potential risk for being in need of long term care services during their life time needs to be made available to our elderly citizens. In the preplanning for its insurance program, the AARP estimated that 11% of its membership under the age of 65 and 20% of its membership over the age of 65 would be interested in purchasing long term care insurance. If we were to apply these percentages to our State's elderly population, one could estimate that 75,000+ individuals would be interested in this product.

Again this year I would like to address the need for establishing a mandatory preadmission screening program for all individuals entering nursing homes. As you know the Community Long Term Care Program currently operates a similar system for all individuals requesting Medicaid funded nursing home care. I am requesting that the Study Committee on Aging consider making this preadmission screening program available to all individuals who are applying for nursing home admission irregardless of the source of payment.

Presently, approximately 25% to 30% of the referrals to the Community Long Term Care Program are individuals who are nursing home residents and who are attempting to convert from private pay status to Medicaid. These individuals have exhausted their financial resources and/or the benefits of other programs such as Medicare and the Veterans Administration. In many cases these individuals have been determined to be ineligible for Medicaid sponsored nursing home care because their level of care needs did not meet the medical criteria established for the Medicaid program. When this situation occurs there is considerable frustration and anxiety on the part of the patients and their families. A preadmission screening program designed to assist individuals in remaining at home irregardless of their source of payment might alleviate these unfortunate circumstances. Early studies performed by the CLTC program have

indicated that those individuals who are converting from private pay status to Medicaid had a median length of stay in the nursing home under private pay status of approximately five months. This means that within the study sample, 50% of those individuals who converted to Medicaid did so within five months of admission. Further break down of the data indicated that over 70% converted within their first year of admission. A mandatory preadmission screening program for all individuals would benefit many of these patients. Through this process they would be able to identify their specific needs which could be met by home and community based services as opposed to institutional care.

To implement a program of mandatory preadmission screening State legislation would be required. Other states are currently utilizing similar legislation to assist their elderly in need of long term care services. For example, the Georgia legislation allows for preadmission screening for anyone who would enter the nursing home and require Medicaid assistance for long term care services within 180 days of their admission. Other the states which have similar preadmission screening programs include Virginia, Illinois, Indiana and Minnesota. I am recommending that the Study Committee on Aging staff work with staff of the State Health and Human Services Finance Commission to develop proposed legislation for consideration during the next legislative year.

The final issue which I would like to address is that of access to Medicaid sponsored long term care services. As I have discussed early the Community Long Term Care Program is getting under way on a statewide basis and soon will be serving approximately 5,000 new Medicaid eligible long term care patients each year. This Program provides an immediate response to meet the rapidly growing demand for long term care services. The Agency currently receives over 1,200 requests for Medicaid sponsored long term care services monthly. Of those individuals who are Medicaid eligible and need skilled or intermediate level of care, 47% choose to remain in the community for service through the Community Long Term Care Program and 53% choose to enter the nursing home. Since nursing home care is not always readily available for our patients, we often provide them with community service pending their admission to a nursing home. As of August 31 there were 209 patients receiving community services while awaiting nursing home admission. This number is the only accurate accounting of the number of Medicaid clients awaiting nursing home admission. We realize there are others who are awaiting placement but our current client system does not provide this information. We do know, however, that over 300 Medicaid eligible clients enter nursing homes each month thus providing opportunities for those awaiting placement to be admitted. In spite of availability of both community and nursing home services under Medicaid there continue to be instances in which Medicaid clients have difficulties accessing long term care services. The Finance Commission has undertaken the study of the need for long term care services including institutional and noninstitutional care. This study should be completed by the end of the year and will be available for use in planning future Medicaid investments for nursing home and community services. In anticipation of the findings of this study, the Finance Commission's FY 1986-87 budget request included funding for an additional 232 nursing home beds. This request was not included in the Budget and Control Board's recommendations, however, we continue to feel strongly that additional nursing homes may be needed in the Medicaid program. Another approach to increasing the availability of institutional based long term care services is also being considered by the Finance Commission. We are currently evaluating the nursing home utilization

control activities which include the mandatory preadmission screening program, nursing home utilization review, and inspection of care in nursing homes to determine if these activities are providing an effective system which will assure that needed care is provided to those clients who qualify for care and that proper use is made of Medicaid funds.

I would like to express again my appreciation for the support and assistance which the Study Committee has given to the Community Long Term Care Program. I look forward to the opportunity of working with the Study Committee during the next year to improve the services which are available to our elderly population.

Representative Blackwell asked if the agency had determined what the unit cost is for level of care screening.

Mr. Brown said that they could develop that information and send it to the Committee. In some states it is between \$50-\$100 per person.

TESTIMONY OF VALERIA BOYKIN-TATE
COLUMBIA URBAN LEAGUE
LEGAL SERVICES FOR THE ELDERLY PROGRAM

The Columbia Urban League Legal Service for the Elderly Program is designed to provide legal assistance to persons aged sixty (60) and over, who reside in the Central Midlands Region. Our advocacy system covers a range of legal services including advise and counsel, drafting legal documents, assistance in the acquisition of and maintenance of federal benefits programs and representation in administrative proceedings. In the past program year we served over 300 persons. Without our service, the majority of these seniors would not have obtained legal service. After paying for their daily living expenses there is very little left from their fixed income to pay for needed legal services.

The seniors of South Carolina have a lot to be thankful for in the area of legal affairs. Several Area Agencies on Aging fund programs for the exclusive provision of legal services to seniors. The South Carolina Bar under the leadership of its new president has indicated a commitment to greater pro bono service and to legal services for the elderly. The Young Lawyers Division of the SC Bar has written a Senior Citizens Handbook which is a guide to laws and programs affecting senior citizens. The SC General Assembly has raised the Homestead Exemption to \$20,000. Indeed the General Assembly appropriated \$9,500 to the Columbia Urban League Legal Service for the Elderly Program and for that we are very grateful, particularly to Senator Lourie and Representative Faber for the work they did in securing those funds for us.

We submit that all of this is an indication of a recognition in the state of South Carolina of the need for the availability and promotion of legal services for seniors in SC. Even with the aforementioned resources, we know too that there is still work to be done to protect the rights of seniors and to insure legal representation of them when their rights have been infringed.

The problem of elder abuse is a national disgrace. It is no less a problem in South Carolina. Countless seniors are abused daily and they are afraid to come forward; convinced that no-one cares. Seniors need to know that their state will stand and protect them when they are abused. We should send a message out loud and clear that elder abuse will not be tolerated in the state of South Carolina; not by the children or other family members of seniors, not by nursing homes and other senior care facilities, not by anyone. We need to make the penalties stiff and enforce them with vigor.

Testimony of Valeria Boykin-Tate
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Fraud on the elderly is also an increasing problem. The elderly are easy prey for unscrupulous practices within and without the market place. These frauds include: insurance, home improvement, land, automobile and funeral frauds. When victimized, the elderly are likely to suffer disproportionate losses and are slower to recover than the general population. Again SC needs to punish those who take advantage of seniors in this way.

Then there is the senior who finds herself in a second marriage with a person who is "not who I thought he was". They are living there last years in misery; they are ashamed of their poor judgement and they want out of the marriage. Yet they cannot afford a private attorney and their income is too high to qualify for legal services. Since our program does not handle contested matters, these seniors find themselves stuck in an unfortunate situation.

The SC General Assembly is currently looking at Probate Code Legislation. We urge the passage of a code which simplifies the procedures for probate and makes it less expensive. The need for uniformity from county to county within the state is very important. If our probate code is similar to other state's codes that eases the burden of those who move to South Carolina.

"Home equity conversion or reverse equity plans are designed to help house-rich and cash-poor homeowners unlock the value of their home and convert it into income, without being forced to move or having to repay the loan from monthly income. Elderly homeowners could draw upon home equity to make repairs on their homes, making the home pay for itself rather than spending monthly income for upkeep. In some cases, the use of equity funds to put in ramps, handrails, elevators, or bathrooms will enable the elderly homeowner to continue to live self-sufficiently. Equity loans also can be used to meet medical and health care expenses. Often such homeowners have monthly incomes too low to qualify for conventional mortgage loans. Home equity conversion allows the elderly homeowners to draw upon the asset represented by their home's value (equity), without moving elsewhere and deferring repayment until a later time. The White House Conference on Aging and the President's Commission on Housing recommended that ways should be found to make equity conversion more available across the Nation. Home equity conversion is a very exciting area; with pros and cons like everything else. It is however, worth learning more about and we should do so for the good of our seniors.

As we look around the Midlands we see it growing. Hopefully our seniors will share in the new life emerging. We should

Testimony of Valeria Boykin-Tate

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address a fair share of our resources to insuring that their interest and rights are protected. South Carolina should continue to promote the legal rights of seniors and the availability of legal services for seniors, thereby creating an environment which is attractive to seniors and one which all South Carolinians can be proud of.

South Carolina Gerontological Society

TO - The Joint Legislative Study Committee on Aging

I am Dr. Harold F. Park, President of the South Carolina Gerontological Society, and am pleased to speak on behalf of the Society.

The South Carolina Gerontological Society is a voluntary organization of persons interested in the needs of older people, of adequate facilities and programs for meeting these needs, for research in gerontology, and for adequate education and training of all persons who work with the elderly or make decisions affecting them.

We are a non-profit organization with members in all areas of the state, who themselves are engaged in dozens of professions and occupations, most of whom are related to education about or services for the elderly.

The SCGS wishes to commend the Legislature for establishing and continuing this Study Committee on Aging. Your task is most important, but complex and involves difficult issues. The SCGS also thanks the Joint Committee for these public hearings and other ways of identifying the problems and concerns of South Carolina's older citizens and receiving information and ideas from all segments and organizations and areas of the state.

Today we express to you four concerns:

1. The South Carolina Gerontological Society supports and urges prompt passage of the Death With Dignity legislation.

It is important for all citizens of South Carolina NOT to be forced against their will to endure artificially sustained bodily functions, but rather to be able to exercise their right to live or die according to natural processes. This is not an endorsement for the taking of life either voluntarily or by imposed intervention. The bills before the legislature last year included sufficient medical and legal conditions and safeguards.

The SCGS endorses and urges prompt passage of the Death With Dignity legislation.

2. The SCGS also urges the passage of the Probate Code revision legislation, which will provide in all areas of the state a more uniform, less cumbersome, less costly process.

We agree with Governor Riley that enactment of the proposed revision of the S. C. Probate Code is urgently needed for the sake of our citizens.

3. The SCGS is most pleased that the Center for Gerontology has been established, a cooperative project of our state colleges and universities.

We commend all those responsible for making this center a reality. There is such an urgent need for studies and research about all aspects of the aging process and how to improve the quality of life for the elderly and for those who care for them.

We, therefore, urge the legislature and the cooperating colleges and universities not only to continue but to expand the funding and support for the Center for Gerontology.

4. The SCGS urges the continuation of the Office of Mental Health Services for the Aging in the Department of Mental Health as a full time position served by a qualified professional educated and experienced in gerontology. We agree that it is important that all government agencies reduce costs where possible without curtailing necessary services to people, but any reduction in this office which focuses on services for the aging is a dis-service and thus short sighted, and soon will result in the need for more services of the mental health agencies with increased costs.

We, therefore, recommend that the Director of the Office of Mental Health Services for the Aging be continued (or re-established) as a full time position and filled by a qualified professional educated in gerontology.

Thank you for this opportunity to present our concerns.

Harold F. Park, President

South Carolina Gerontological Society

% Lutheran Theological Southern Seminary
4201 Main Street
Columbia, S. C. 29203

SC COMMISSION ON WOMEN

Statement to Committee on Aging 10/2/85

Clelia D. Hendrix, Chairperson
Alberta S. Rowe, Commissioner & Presenter

The S.C. Commission on Women greatly appreciates the opportunity of making this presentation today.

We would again solicit your continued concern for the unique problems of elderly women - especially the four areas which we underlined in our 1983 statement to you:

1- Safety, 2- Health, 3- Financial Security and 4- the Quality of Life.

The South Carolina Commission on Women know that the needs of women in our state and the needs of all older citizens overlap. Statistics tell us that all women should be concerned about legislation for the elderly because they are and will increasingly be the largest population of our older citizens.

While there are many areas which demand legislative attention, we ask that you join us in support for the passage of the Proposed S.C. Probate Code, including an elective share for spouses, which we believe will ease the burden on surviving spouses.

We also encourage your attention and support for the Equitable Distribution of Property at Divorce bill first introduced in 1981 with Women's Commission assistance, and the Homestead Exemption increase.

Finally, we recommend an analysis of the model state bill for Respite Services for Caregivers for your consideration. Respite care is one small, but much needed step in relieving the burdens of fulltime caregivers, the majority of whom are themselves elderly women. Not providing community support for caregivers, society could well find itself with two(2) dependent adults instead of one, with both persons dependent on public support for their survival.

Thank you again for this opportunity to present our priorities, and for your concern for the life circumstances of SC's senior women. The South Carolina Women's Commission will welcome any future opportunities to assist you in addressing these issues which affect so many of SC's citizens.

Loretta Brown
Suite 155 Dutch Plaza
800 Dutch Sq. Blvd.
Columbia, SC 29210

PUBLIC HEARING PRESENTATION
THE SOUTH CAROLINA LEGISLATIVE STUDY COMMITTEE ON AGING
BLATT BUILDING, ROOM
COLUMBIA, SOUTH CAROLINA
OCTOBER 2, 1985

Mr. Chairman, members of the Study Committee on Aging, thank you for giving me the opportunity to present testimony for your consideration. My name is Loretta Brown and I represent the Central Midlands Regional Planning Council. I currently serve on the Council as a representative of Richland County and I chair the Regional Aging Planning Advisory Committee.

Central Midlands, as the Area Agency on Aging, has provided leadership in the areas of planning, program development, program coordination, and training for more than ten years. During those years, the staff of our Area Agency on Aging has grown in experience, knowledge, and capacity. We have been able to do this because of a good foundation on which to work--the Central Midlands Regional Planning Council.

Currently the South Carolina Commission on Aging and the South Carolina Governor's Office are conducting separate studies which involve Area Agencies on Aging. The Commission's study is concentrating solely on Area Agencies, while the Governor's study is looking at the Aging network as a whole. Both studies are being conducted to determine the structure of agencies which will provide the most effective and efficient services for our aging population. The Central Midlands Regional Planning Council supports these efforts and has offered our opinion on their directions at the appropriate times.

As we have stated to you in the past, we feel the most effective system of services to the elderly of our state can be accomplished through the existing network of agencies as outlined in the Older Americans Act. Those agencies are first, the State Unit on Aging; second, the Area Agencies on Aging; and third, the service-providing agencies. Each is defined as a separate entity by law, and the State and Area Agencies have been given the responsibility to bring all available resources to bear to meet the needs of our aging population. Those resources are not limited to the Older Americans Act but are defined to include the Social Services Block Grant, Medicaid, Urban Mass Transit funds, Housing and Urban Development funds, etc. In other words, our state should look at consolidating all programs for the elderly under the authority of this state's Single Unit on Aging and the Area Agencies on Aging.

Other issues of importance that will come before you this year include the Death with Dignity Bill (House Bill 2041), the Probate Code, and the Community Services for the Elderly Legislation. Passage of both the Death with Dignity and the Probate Code issues are long overdue. This state's reluctance to honor the opinions of the older people themselves on these issues can be seen as little more than "feet dragging" at its worst. We need to move on toward passage of these important Bills this year.

The Central Midlands Area Agency on Aging again supports passage of the Community Services for the Elderly Legislation. This law is needed to provide the resources needed to develop a community services network throughout South Carolina.

Many opponents of this legislation point to the Community Long Term Care Program as a save-all for frail elderly in need. Community Long Term Care was not designed to meet the needs of the elderly population who are frail but not immediately in need of nursing home care. The target population for Community Long Term Care is minute when compared to the population with the need for in-home and out-of-home care to prevent institutionalization in the years to come.

If South Carolina cares for its elderly citizens, the Legislature will not hesitate to move forward on this law this year. The time for passage of this is long overdue.

Finally, I would like to comment on an area of growing concern to the aging network, to older people, and to the families of elderly persons--Alzheimer's Disease. As Dr. Sue Scally pointed out in her presentation earlier today, more than 20% of all persons over 80 years of age suffer from this disease. Twenty percent, or one in five people, over 80 years of age have Alzheimer's. This means that probably at least half of the families in this state and nation are having to deal with the effects of this dread disease without any real support or encouragement.

Dr. Scally has laid out a number of issues for your consideration, with potential courses of action. We urge you to take a very pro-active position on these issues now, and then to continue to work with the Advisory Committee on Alzheimer's Disease and Related Disorders, which was created by the South Carolina Commission on Aging.

This concludes my remarks today. Thank you again for allowing me this time, and I will be happy to answer any questions you might have.

Presentation 10/2/85 to Joint Legislative Study Committee on Aging

Presented by: Edna Swartzbeck, RN, MN
Clinical Nurse Specialist, Discharge Planning Unit
Dorn VA Medical Center

I have been asked by Mrs. Joan Kershner and our Hospital Director at the Dorn VA Medical Center to share with you a program for older veterans that we have had in operation since 1978.

The program I am referring to is called a Discharge Planning Unit. It is a Nurse Administered Unit and I am the Clinical Nurse Specialist in charge of the program. We have 19 beds for this program on the Medical Service. In April of this year we added an additional 10 intermediate care beds.

Patients requiring an extended period of hospital stay are referred by the medical and surgical residents and staff physicians. These patients are somewhere between acute care and outplacement and do not require daily physician monitoring. Patients come to the unit with a summary and prescribed medical regimen.

My initial assessment is concerned with their present medical status, their functional ability as it relates to mobility, nutrition, bowel and bladder control, vision, hearing, dentition, mentation and in general what is required from a medical/nursing social standpoint to get this patient back home if possible. If not home to the appropriate level of care.

I have clinical privileges to request and evaluate diagnostic data when new pathology occurs, utilize all services and medical specialists and an excellent internist whom I can consult when other than simple medical problems arise.

Our focus is a multidisciplinary approach utilizing all of our rehabilitation medical services, dietetics, social work service, speech and audiology, ophthalmology, chaplains etc.

We involve patients and families in the patient teaching and invite families to participate in the care. If patients have tubes we try to get them out or to teach the family member or significant other how to care for the patient with, for example, the feeding tube in place. Other examples are care of the skin, prevention of or treatment of decubitus ulcers, the care of problems with incontinence, medication administration and nutrition. Care of the patient with altered mentation is a very real obstacle to getting patients home.

The age of these veterans is well over 65 and many are well into their 90's.

The average length of stay is approximately 25-30 days but there have been a few cases where the stay has reached 12-13 months.

Since the inception of this unit in 1978 approximately 2,000 patients have been transferred into and from the program.

-52% have gone home or to Residential Care Homes.

-38% have gone to community nursing homes or other state or Federal facilities such as Tucker Center.

-4% have been transferred back to acute care - many who become acutely ill are treated on the unit.

-6% have died.

It must be stressed that patients are never denied access to a physician. The cost effectiveness of this nurse administered unit has not been examined but is probably reasonable to say that the cost is considerably less than on units where there is daily physician monitoring.

The multidisciplinary discharge planning team meets weekly to tie together the patients progress as viewed from each discipline. The patient and family frequently meet with us. Our focus is on trying to maintain the integrity of the family unit. The patient and family are very much involved in the decision making.

This is often a very fragile population with multiple chronic problems who often do not stay medically stable for very long periods. As I said earlier, our focus is on trying to get the patient home. The spouse, if there is one, is often as fragile as the veteran patient and in many cases going home is unrealistic. In fact, there are more and more cases in our long lived population where the children of our patients are well over 65.

We try very hard to consider the needs of the entire family and to harness the available community support systems. Most of those going home are ^{LINKED} ~~married~~ up with the home health nursing service and provisions are made for follow-up medical care. Needless to say, this program has been the most rewarding experience of 34 year nursing career.

One of the very real needs, on my experience, has been for additional funding for home health aids and sitters and the availability of and funding for live-in help to provide personal care, supervision of safety, companionship, light house-keeping, shopping and transportation. The costs of even this level of services is prohibitive to many of our veterans and I expect to many other limited income elderly in the community.

It seems quite apparent that in some cases these services could be provided at home at considerably less cost than the \$55-\$75/day for a nursing home. Most importantly it would permit the frail, fragile and disabled elderly to remain in the familiarity of their own homes surrounded by their loved ones and their treasured possessions.

RESOLUTION

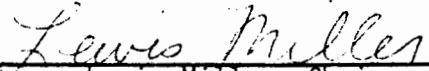
WHEREAS, the South Carolina Appalachian Council of Governments Board of Directors were informed of the South Carolina Commission on Aging's study of possible reconfiguration of Area Agencies on Aging in South Carolina,

WHEREAS, the South Carolina Commission on Aging has received the results from the Urban Systems Study and their own staff study as well as information from four public hearings concerning the reconfiguration,

NOW, THEREFORE, BE IT RESOLVED by the South Carolina Appalachian Council of Governments Board of Directors that:

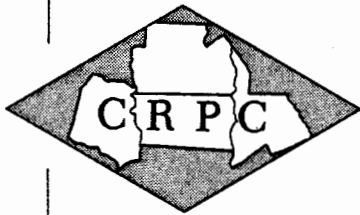
The South Carolina Appalachian Council of Governments is determined to continue in the role of Area Agency on Aging within the existing service area.

Adopted at the South Carolina Appalachian Council of Governments Board Meeting on September 27, 1985.



Lewis Miller, Chairman

OCT 03 1985



CATAWBA REGIONAL PLANNING COUNCIL

Suite 300, SCN Center

100 Dave Lyle Boulevard

P. O. Box 862 Rock Hill, S. C. 29730 Tele. (803) 327-9041

September 30, 1985

Mr. Patrick Harris, Chairman
Joint Legislative Study Committee on Aging
335-D Blatt Building
P.O. Box 11867
Columbia, SC 29211

Dear Mr. Harris:

This letter is being written on behalf of the Catawba Regional Planning Council's Aging Advisory Committee, consisting of 24 members from York, Chester, Union, and Lancaster counties. As an advisory group, we are concerned with various policies and legislation that affect our elderly citizens.

Our advisory members would like to present two areas of concern to your committee hearing for review. The first concern relates to the Probate Code which has not yet been passed by the Senate. We would like to express our support for passage of the Probate Code bill. This bill is long overdue and is needed to rectify and simplify the present probate system which has created problems for many people, both young and old.

Our second concern relates to the problems many elderly people have resulting from illness and hospitalization. Medicare coverage and related policies of DRG's have caused serious and distressful situations for many sick, elderly people. Numerous older people who are dismissed from the hospital continue to need extended health care and often do not have the family support or resources needed for continued in-home care. Many of these early dismissals result in re-entry into hospitals which is neither cost-effective nor beneficial to the patient.

We hope that your committee feels that both the passage of the Probate Code and better health care for the elderly are relevant and justifiable concerns. We appreciate your consideration and any action that can be taken in resolving these problems and meeting the needs of the elderly people of our state.

Sincerely,

Allen Edwards, Chairperson
Catawba Aging Advisory Committee

Joint Legislative Study Committee on Aging



State of South Carolina

HOUSE MEMBERS:

PATRICK B. HARRIS, *Chairman*
DILL BLACKWELL
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Director of Research

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DR. C. JULIAN PARRISH, *Secretary*
MRS. GLORIA H. SHOLIN
DR. J. CARLISLE HOLLER

1985 LEGISLATIVE SUMMARY

335-D BLATT BUILDING
P.O. BOX 11867
COLUMBIA, S.C. 29211
(803) 758-5259

During the 1985 session the General Assembly sought to meet the needs of older South Carolinians by passing several significant pieces of legislation.

The following bills were introduced by the Joint Legislative Study Committee on Aging and passed by the General Assembly:

Community Services For Functionally Impaired Older Persons

The General Assembly appropriated \$250,000 to the SC Commission on Aging to establish a program of community services for frail older persons without regard to income eligibility or level of impairment. These services may include homemaker, respite care, adult day care and medical transportation.

Homestead Exemption

The period for application for Homestead Exemption was extended from January to July 5 (instead of May 1) for 1985 only.

Commendation To Hyman Rubin

Former Senator Rubin was recognized and commended for his eighteen years in the State Senate and his service as chairman of the Senate Medical Affairs Committee and as Chairman of the Joint Legislative Committee on Aging.

Bill of Rights for Residents of Long-Term Care Facilities.

The purpose of this legislation is to provide residents of long-term care facilities the opportunity "to live within the least restrictive environment possible in order to retain their individuality and personal freedom."

Residents are entitled to the following: a description of their diagnosis, plan of treatment, and prognosis in terms easy to understand; management of their own personal finances (unless the facility has been delegated in writing to carry out this responsibility); to be free from mental and physical abuse and free from chemical and physical restraints except those ordered by a physician; security of personal possessions and confidential treatment of personal and medical records; respect, dignity and assured privacy during treatment and when receiving personal care; privacy in communications and association; and other basic rights. Each long-term care facility must establish grievance procedures to be exercised by or on behalf of the resident to enforce the rights provided by this act.

Other items in the 1985-86 State Appropriations Act which affect older South Carolinians include:

Hearing aids and their attachments are exempt from sales tax beginning July 1, 1986.

Retired pay exempted from State income tax for civil service, military and certain others has been increased from \$1200 to \$2100.

A state retiree whose most recent employer prior to retirement is participating in the Group Life Insurance Program, will qualify the beneficiary for death benefits of \$1000 for 10 years service, \$2000 for 20 years and \$3000 for 30 years.

A 1% bonus from the General Fund will be paid to State retirees as a 13th check at the end of November, 1985.

Persons 65 or older are exempted from the seven dollar increase in license tags and will pay \$10.00 for 1985-86.

The second session of the 106th General Assembly has the following legislation of interest to older South Carolinians pending:

Death with Dignity, H.2041, passed the House and is pending third and final reading in the Senate. This bill would legalize a "Living Will", recognizing the rights of an adult to make a written directive instructing his physician to withhold or withdraw life-sustaining procedures in the event of a terminal condition.

Mandatory Retirement, H.2698, S.447, is in Committee in both Houses. It provides that no person whose compensation or any portion thereof is paid from public funds may be required to retire from or leave employment on the basis of age alone, excepting law enforcement and fire fighting personnel.

Probate Code, H.2792 passed the House and is in the Senate Judiciary subcommittee chaired by Senator Thomas E. Smith, Jr., Florence. Public Hearings will be held on the bill in the fall of 1985.

This bill provides for the South Carolina probate code which consolidates and revises aspects of law in this state relating to the general probate definitions, provisions, and jurisdiction, intestate successions and will, probate of wills and administration of decedent's estates, local and foreign personal representatives protection of persons under disability and their property, non-probate transfers, and trusts and trust administration.

The Joint Legislative Committee on Aging determines its legislative priorities following a public hearing held each fall. An annual report is presented by the Committee to the Governor and the members of the General Assembly. Copies may be obtained from the office of the Committee.

JOINT LEGISLATIVE STUDY COMMITTEE ON AGING

335D. Blatt Building, Columbia, SC 29211

Telephone 758-5259

Representative Patrick B. Harris, Chairman, Anderson
Representative Dave C. Waldrop, Jr., Vice Chairman, Newberry
Dr. C. Julian Parrish, Secretary, Columbia
Senator William W. Doar, Jr., Georgetown
Senator Isadore E. Lourie, Columbia
Senator Peden B. McLeod, Walterboro
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